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TO BE OR NOT TO BE A KIDNEY DONOR:
A parent's personal principle - cause for patient's death

Abstract

In the cultural and bioethical process of *attitude change* towards live-donor kidney transplant, how could personal character-principles be a destructive *change agent* with detrimental impact upon a daughter's life, after father's refusal to be the only compatible live donor? The refusal to save the 27 year old life resulted in her death. Research examines real data: parental impact upon family-belief-system of his child, and later upon her death. Case study: Lupus Nephritis terminal stage renal failure patient (from age 15), on dialysis for 11 years. Controversial findings point to personal ethical and cultural convictions that prioritized concerns about marital stability and family reaction, to life of his daughter from first marriage. General data is given on Macedonian recent increase in kidney transplants from live donors, as a positive context juxtaposed to loss of life resulting from self-centered value systems and rejection of daughter's plea for his kidney. Sequence of events leading to patient's death at age 27 are documented in hospital and health care environment settings.

Kay words: personal principles, parental bias, declined kidney donation, death

Introduction:

There are negative religions, as there are negative medical or law practices (malpractices; there is ultimately inhumane human organ trafficking, and there are unthinkably selfish, utilitarian parental treatments of (their own) children. May this informed evidence and engaging questions contribute to the celebration of life over death-sentence pronounced by rejected kidney donation; may it be celebration of never antiquated parental love over parental right to make a biased choice for not saving life of one of his children, under the pretext of not offending his other children.

The prospect for printing kidney organs for transplant-on-demand is perhaps approaching faster than projected. What remains uncertain until that digital transplant revolution, is the ethical question: are parental rights, or obligations, going to be declining from serving life-preserving

purposes, assuming that parental own kidney donation is not considered a universal ethical conscientiousness, but a personal and relative principle, an individual choice *to give or not to give a second life chance* to its biological child?

This question imposes consecutive ones, related to different but related contexts, such as: how much will genetics remain a factor and precursor to ethical parental response in saving human life when in-vitro children might opt to claim their *parents'* ethical obligation to donate their kidney in addition to the previous semen donation, however this time within a new ethical choice: to prefer to save the in-situ or the in-vitro child. Answers to this dilemma will also depend on diversities in social-cultural, legal-medical, besides individual concepts of responsibility within the meaning of love, and its core values that have been dramatically polluted by the residues and mutations of the post-religious, post-historic and post-human age.

Bioethics, ethics or morals in culture and literature are still being conventionally viewed as transmitters (conductors) of recorded history of knowledge and imagination, theories and assumptions, with projections for future affirmative, or newly deconstructive, approaches to life, to medical technology and to adapting law.

Honoring the affirmation of life and preservation of lessons learned from a life-death case in favouritism and utilitarianism, this paper surveys a brief history of a parent's ethics and a patient's *dependence* on that parent's informed decision to sentence the patient-child to death, or life. Personalities in this case survey are not given their real name, for the purpose of protecting involved individuals from any legal actions and preventing any lawsuits.

The freedom of parental choice in this survey is based on the father's individual right to say "yes" or "no" to his daughter when she made her first and final plea: to have her father as her only possibly live kidney-donor, amidst her terminal renal failure, and after dialysis for 11 years. The father had previous knowledge of his daughter's long and devastating battle with Lupus Nephritis, dialysis, endocarditic and recurring SLE, systemic lupus affecting different organs. This knowledge might have presumably increased a parent's awareness of his "first" daughter's immediate need for his life-saving kidney donation, and thus convinced him to prolong her life-expectancy or stabilize her quality of life. Nevertheless, parent's adamant response to his daughter's plea to save her life with his kidney, had been: *"No, it is out of question to even talk about my kidney. I have two other children, and wife. Let's never mention this donation again".*

Parent's response was a final negation in daughter's hope for life, and for father's love. Father's reply became immediately known to members of medical team involved in patient's treatment at University hospital ICU. Their medical, and human, ethics was not ready to accept his negative response and foresaw the utterly devastating consequences for their gravely-ill patient, in addition to the psychologically devastating effects upon their patient's life as "irrelevant in her father's self interest".

Medical professors and assistants had already tried for 10 days to save this patient's life, and learned that compatibility of the father's blood remained the only option for her survival. After the relentless battle with the Lupus inflamed blood vessels and platelets, which necessitated 11 units of blood transfusion, following 4 litters of blood loss, the medical team resorted to this rare instance of medical ethics right and obligation to save her life: Prior to patient's hospital discharge, medical experts approached her and insisted that she openly ask her father to donate his kidney to her, without delay and without accepting *no* for an answer. Patient initially refused this suggestion, but reluctantly agreed to it.

Father's refusal to donate his kidney to his terminally ill daughter, became immediately known to the involved doctors, as well as to patient's family, as daughter confided his reply that threw her in despair. This event could be testified by closest and wider family members, regardless to father's later claims in self-defense that his daughter never approached him with this question, that she, or her mother, fabricated his refusal. Furthermore, the father threatened with legal action and lawsuit, to protect his personal and professional status.

One of his actions against the daughter's true testimony about his refusal had been the following: Soon after the daughter's death, the father forced under pressure the editor of a book published in memory of the patient, to confiscate every copy and ban further distribution. The book was a testimony of daughter's intellectual brilliance, moral excellence and physical endurance, and was written by patient's mother, who had no other children. In addition to the book confiscation and banned distribution, the father threatened with additional legal action: to confiscate all mother's possessions and put her in prison - for *allowing* daughter's testimony about his refusal to donate his kidney be known to the readership. Father refused to accept that patient-daughter already confided her truth to others, in expression of her most painful realization that her own father did not show any generosity or empathy for her. Father decided to

believe that his daughter's death will automatically cancel her out as personal witness, and exclude further direct proof of his rejection to help her.

Described parental response imposes several ethically relevant questions:

1. SAVE A DYING CHILD OR SAVE RESPECT BY OTHERS

Does the father legally have family rights, or personal human rights, to *sentence* his daughter to *no-life-prospects*", in order to preserve his image of a better parent for his other children from the current marriage, while he destroys his father-role in the eyes of the daughter-victim (who had been widely known for her character integrity, love for family and empathy for other)? Therefore, what would ethically be right:

a) to save the dying child, from the failed marriage, or

b) to save the trust of the existing children (from the newly maintained marriage)?

NOTE: For six years the father had hidden the truth from his children with another mother: that he has had yet another daughter, and had had a previous marriage.

2. FATHER'S KIDNEY OR DAUGHTER'S LIFE

If the father agreed to be a kidney donor and remained with one kidney,

a) will the "cost" of this parent's loss of one kidney be a greater loss, or

b) will the "cost" of his daughter's life be a greater loss?

NOTE: With the father's kidney transplanted to his daughter a maximum medical rehabilitation could have been achieved, in addition to the enhanced social and personal closeness of parent/patient-child, which has been dysfunctional most of the time. Also, parent's kidney connected to the child's body (mutually connected arteries and veins) would have achieved both bio-physical and metaphysical bond, a compensation for the lost years of family closeness.

3. GREATER GOOD: WIFE OR CHILD

Is parental health with only one kidney, going to reduce his marital happiness, in contrast to his parental ethics as a potential life-savior for his daughter? Therefore:

3.1. What is a greater good:

a) the father to prove his love to the other wife, by saving his kidney for her, or

b) the father to prove his love to the child from the previous wife, by saving her life?

4. GREATER VALUE: PARENT'S HEALTH OR CHILD'S LIFE

Under the assumption that patient's Lupus might go into remission, or could be treated with plasmapheresis, so that the transplanted kidney prospects for organ survival are secured, although father's and daughter's health safety might be equally compromised,

4.1. Could there be ethical priority between

a) value of parent's health as kidney donor, vs

b) value of his child's life as a kidney recipient

NOTE: Daughter-patient discussed with Georgetown and Johns Hopkins university hospital transplant teams, the outcome of plasmapheresis treatment for reducing the antibody counts, in preparation for prospective kidney transplant. Opinions she received varied from 6 to 30 plasmapheresis treatments might result into possible Lupus remission, enabling a longer kidney transplant survival, with addition support by anti-rejection drugs. This was also known to the father who later refused to be a live-organ donor for his child.

II. The above ethical questions had generated a list of sub-questions among medical, legal and general community. Some of them are basis for further relevant discussions:

1. If the father was knowledgeable of higher death-rate when kidney is donated much later, after a prolonged and health-deteriorating dialysis treatments, why didn't the father himself initiate self-testing for a *preemptive transplantation* of his kidney to his daughter, without allowing the daughter to beg him for life, and undergo a detrimental, stress-related Lupus flare-up? Was it more ethical for the father to offer his kidney on the very onset of his daughter's immunological disorder (Lupus Nephritis), at age 15, to prevent chemo dialysis, peritoneal dialysis, multiple subclavial catheter surgeries, numerous hospitalizations, and ultimately death?

2 Is the father's attitude of *wait and see* more ethical than *try and help* before the Systemic Lupus Nephritis further inflicts irrecoverable damage to the young body? Being a medical doctor himself, aware of the critical high sensitivity health status of his daughter, was it ethical to not prevent all possible life-threatening complications she experienced from Lupus Nephritis: cardiovascular problems (endocarditis); hepatitis B; repeated inflammation of various organs; exposure to doctor-prescribed pain-killers for excruciating pain in various affected organs, etc.?

3. Is it ethically right for the father to hear about other people's charitable donations honoring his daughter's life-needs (a leading company donated live-cells treatment in a foreign country), but does nothing to donate his own time and resources to research and suggest new treatments, if he would not allow his own kidney to be donated to the daughter-patient?

Quotes from the latest film on the holocaust "Night will fall" might be fitting the horrors a patient goes through while waiting the life persecution for not having a *kidney-licence* to live: "*Hard to describe ... find myself in the world of a nightmare... starving woman"* (starving for health, for food, for drinks... starving for sleep, for freedom from dialysis, freedom to dream)

III. MACEDONIA PROMOTES LIVE-KIDENY DONATION

Health wars with increased kidney diseases contributed to the first life-donor kidney transplant in 1953, and the first successful kidney transplant in 1959, both in Paris, France. These procedures took place when no medical technology or advanced research could guarantee expected outcomes for the kidney recipient, although parental and family readiness to sacrifice their kidney were much higher due to stronger traditional moral readiness to sacrifice for the one in need, despite biblical disagreements over transplants.

After the first successful kidney transplant in the U.S., Boston, 1954, it took 23 years for the Republic of Macedonia to undertake its first kidney transplant in Skopje, 1977. Under the influence of Marxist atheist philosophy and the Yugoslavian communist social-utopian ethics, almost no kidney transplant surgeries have been performed in the Republic of Macedonia, the last one taking place in 1989.

A qualitative change was introduced at the beginning of 2013, with the new Transplantation Law in Macedonia, based on existing European laws, structured by legal and medical experts. Responding to this legal regulation, 50 patients received live-donor kidney. This helped Macedonia resume the 9th place internationally. Most importantly, these transplants saved 50 lives in less than two years, 50 souls for whom the "*Night will not fall"* into non-filtered, non-dialysed poisons, but the "Day will rise" free from bondage and 21st century *dialysis slavery.* Concusion: *"To be or not to be a kidney donor"* could serve as a compelling testimony of a tragic personal and medical outcome that could have been prevented - should father's love prevailed over his personality traits, partiality or dogmatic principles.

There are crimes committed in organ-trade, and there are undisclosed crimes committed by parental consent. Both of them could try to defend themselves, and might succeed in it, or in their unsanctioned actions. However, the *"universe is listening, and watching, and recording"* the medical, legal, ethical, and religious fields as well. This is not a new-age spiritualism, but science of both metaphysical and physical laws studied by Galileo, Leonardo, Newton, Einstein, Hawking, and of the patient-daughter in this testimony, who believed in the Supreme Being humans called God.

Unless parents, family and community learn the lessons in choosing life over egotistical, self-gratifying interests, *millions of nights will keep falling against the bright days of humanity*. Like the night fallen over the patient whose parent released himself from obligations to "sacrifice" for his future days through his *fallen offspring*. Was it a father's human right to refuse the kidney donation for his child is another ethical dilemma, which detaches itself from Christian ethics, one that the father-non-donor, did not subscribe to.

On a global scale, however, kidney diseases, dialysis treatments and transplant needs are being increased, alongside with human organ trafficking, and "kidney crimes". Within the increased lack of available organs, the refusal to consider live organ donation is also becoming a critical ethical issue of wide proportions, particularly due to diversity of cultural, ethnic and religious communities. May this testimony be an ethical tool against specific *crimes of denied life-donation*, where no informed decision-making could reach informed consent to prevent death.

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