Between a rock and a hard place: the incommensurate ethics of emotionally-related living organ donation

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ABSTRACT

At the end of 2007, over 71,000 candidates in the United States were awaiting a kidney transplant. That same year, 16,622 kidney transplants took place [1]. The growing shortage of organs in the face of escalating need has placed pressure on transplant centers to accept organs from voluntary living donors. Emotionally-related living organ donation (ERLOD) is becoming increasingly common. In ERLOD, donors and recipients are genetically unrelated but linked by close emotional ties. In the case of kidney transplants, ERLOD achieved over 90% success rates after only one year [2]. However, the significant need and efficacy of this practice are not sufficient for its justification; this program must also be ethically acceptable [3]. Living organ donation in general raises concerns regarding the acceptable standards of medical practice and ERLOD in particular poses unique challenges. This article examines, within a clinical care framework, the ethical concerns surrounding ERLOD and why these concerns may be difficult to reconcile from this perspective alone. Discussion may benefit from using the ethical framework of clinical research in adjunction with the clinical care framework to offer a more flexible scope of analysis.

The following case will form the focal point of this article:

Mr. A is a middle aged man with chronic renal failure and has been on continuous ambulatory peritoneal dialysis (CAPD) for the last three years[1]. Since then, Mr. A has experienced bouts of depression and chronic fatigue. He often lacks the energy required to perform simple tasks. This frustrates him and adds tension to his family dynamic. His romantic relationship with his wife has also suffered. Recently, a consulting nephrologist mentioned the possibility of unrelated kidney donation from his wife. The A's have been happily married for 25 years and care very deeply for each other. While Mrs. A was enthusiastic, Mr. A was initially reluctant for fear of the risks involved. Mrs. A did not try to pressure him. After a month's deliberation, Mr. A. accepted the offer because he believed that they would both benefit enormously in the long term. The couple has two teenage daughters, but has not yet discussed the potential donation with them [4].

The major ethical dilemma in ERLOD is determining whether it is ethical for a healthy person to be permanently injured for the benefit of another [3]. Central to this debate are considerations of autonomy, risk/benefit proportionality, and the nature of the relationship between the donor and the transplant physician. Ethical guidelines for medical practices differ depending on the context, as demonstrated by the distinct duties of physicians and investigators in clinical care versus clinical research. These differences are mainly due to the different goals of these practices. The primary aim of clinical care is to provide optimal treatment for an individual patient. Physicians assume a therapeutic obligation as well as a duty to act in the best medical interest of their patients [5]. In contrast, the ultimate goal of clinical research is to improve the health of future patients through the generation of generalizable knowledge [6]. Researchers are ethically exempt from the therapeutic obligation and that of beneficence [7]. Instead, they must demonstrate respect for their subjects as persons by minimizing harm, respecting autonomy, and protecting them from exploitation [8].

As a clinical procedure, ERLOD opposes the traditional goals of clinical care. It neither serves the donor's best medical interest nor provides individualized care, as the health needs of another patient are the driving force behind the transplant. In this way, the goals of ERLOD may be more aligned with those of clinical research as the ultimate benefactor is not the patient being treated. However, ERLOD remains a clinical endeavor because the outcome is therapeutically rather than experimentally oriented [9]. This same inconsistency exists in the donor-physician relationship. It is distinct from the traditional fiduciary relationship of clinical medicine because the mutual aim is to benefit the recipient while minimizing harm to the donor [10]. However, their interaction remains a "clinical encounter" [11], so the traditional obligations of the physician cannot be entirely overlooked. Given these complexities, examining Mrs. A's case from a single ethical perspective does not allow for an appropriate scope of analysis. Rather, it is more fitting to use the fundamental principles of medical ethics as a basis to incorporate perspectives from both clinical care and clinical research. Evaluating the ethics of ERLOD requires consideration of patient autonomy. This analysis is limited to the framework of clinical care because respect for autonomy must be balanced against the physician's therapeutic obligation and duty to act in the donor's best interest [3]. Conversely,

1 This is a portable system in which waste is filtered into a sac that is permanently attached to the abdomen, which must be drained 4 – 7 times a day (www.renalpatients.co.uk/capd)

within the framework of clinical research, the key question is not whether to prioritize donor autonomy over beneficence but whether their autonomy is being expressed [12]. Allowing the subject to determine the limit of acceptable risk is part of respect for autonomy, provided that the standards of informed consent are maintained [13].

An essential component of informed consent is the concept of competence. Questions have been raised regarding the competence of emotionally-related living donors because of their relationship to the recipient. As Mrs. A clearly values her husband, she may not fully consider the risks to her own health before offering to donate. Consequently, her decision may be based on limited understanding. However, competent decision-making is based on an evaluation of risks and consequences according to one's own priorities and values. In addition to a patient's health, this includes consideration of how their lifestyle, family, and friends will be impacted by a given procedure [14]. From Mrs. A's perspective, the welfare of her husband may take priority over risks to her own medical health, and the relative value of the two is entirely subjective.

A second component of informed consent is voluntariness. In order to be voluntary, the donor's consent must be free from undue influence and constraint [15]. In the current case, Mrs. A could feel obligated to donate due to external pressure from other family members or by an internal sense of duty towards her husband and their relationship. However, this does not necessarily constrain her voluntariness. The concept of autonomy within the context of family is not independent, as the interests of family members are often inextricably connected [16]. Because Mrs. A values her husband so highly, fulfilling a sense of duty by donating to him may be an expression of her autonomy, rather than a constraint [3].

While the above considerations are necessary for ethical ERLOD, they are not sufficient. Since the interaction between donor and transplant physician is deemed a "clinical encounter", the donor is considered a patient [17]. Consequently, the physician must analyze the risks and potential benefits of transplantation to the donor individually. The medical risks involved in unilateral nephrectomy are relatively low, with good recovery rates and minimal post-operative reduction in renal function [1]. However, the operation causes definite harm by removing a healthy organ [16], and exposes the donor to the general risks of surgery. Should the donation fail, Mrs. A could also experience psychological harm from depression, anxiety, or regret [2]. According to ethics of clinical care, these harms are justified only if outweighed by potential benefits to the donor, rather than the recipient [14]. While there are no medical benefits to Mrs. A, donation may improve her overall welfare. Because of her relationship to Mr. A, she would likely receive significant psychological benefit from his restored health. Mrs. A's quality of life would also likely improve. Chronic organ failure disrupts the family dynamic, and can lead to caregiver burnout [18]. This demonstrates how assessments of risk/benefit proportionality depend on personal value judgments [19]. The physician's medical expertise does not render him better able to assess the donor's "best interest overall" [20]. While he can empathize and acknowledge the risks and potential benefits, only Mrs. A can judge their relative proportionality.

A further limitation within the 'care' framework is the transplant physician's duty to provide individualized care to the donor. In ERLOD, it is difficult to view the donor in isolation from the recipient because the medical outcome of one patient affects the welfare of the other, and vice versa. Rather, the donor ought to make decisions that take into consideration the impact on themselves as well as their family; not only in terms of health benefits but overall quality of life [14]. The interdependent nature of risks and benefits in this case further limits the ability of the physician to determine 'best interest overall' and subsequently, the applicability of the traditional 'care' framework.

The above issues may be circumvented if considered within the ethical paradigm of clinical research, where the physician's actions may be ethically undertaken for a purpose other than serving the medical interest of the patient. In this context, the patientphysician relationship is protective rather than fiduciary [21]. This shifts the duty of the physician from tailoring treatment to the donor's best medical interest to demonstrating respect for their welfare [22]. In Canada, the Tri-Council Policy serves as the benchmark for ethical conduct in clinical research. The foundational premise of this policy is the duty to demonstrate respect for persons, concern for welfare, and justice. Respect for persons incorporates obligations to respect autonomy. Concern for welfare requires a favorable risk/benefit ratio, but "in keeping with the principle of respect for persons, participants make the final judgment about the acceptability of this balance to them" [23]. This approach intrinsically respects both the importance of quality of life values in risks/benefit analysis and the doctor's limited capacity to make these judgments. Instead, the physician takes on a role that he is competent to fulfill: facilitating patient decisionmaking by communicating the necessary medical information. Finally, the clinical research framework allows for the integration of donor and recipient risk/benefit analysis. Because of the intimate relationship between Mr. and Mrs. A, it is appropriate to consider recipient benefit in relation to donor risk in a similar manner.

In the real world, most transplant centers adopt a highly nuanced approach to evaluating the acceptability of ERLOD and consider potential donors on a case-specific basis. In addition to the factors listed above, this involves assessment of donor motivation, relation to recipient, and psychosocial and physical health. Donor assessment does not fall to the transplant physician alone, but to healthcare teams that include social workers, consultants, and psychiatrists. Furthermore, transplant centers across North America determine their own parameters for the acceptability of ERLOD. This approach maximizes the autonomy of both the donor and the transplant team and avoids many of the conflicts encountered above. However, establishing guidelines with respect to ERLOD is necessary to ensure ethical consistency and fair treatment of all patients [24]. Many of the issues raised by ERLOD result from the restrictions placed on the

patient physician relationship within the framework of clinical care; namely, the duty to act in the patient's best interest (and therefore determine what the best interest is), and to provide individualized care. Due to the distinctive goals and outcomes of ERLOD, this may not be the most appropriate framework to use. This is not to say that the ethical framework of clinical care should be abandoned, but rather that the exceptional nature of ERLOD may necessitate an adjusted approach. By removing the requirements for individually beneficial care, the ethical paradigm of clinical research provides a more flexible framework for consideration of the non-medical factors involved in ERLOD.

AUTHOR'S NOTE

A full discussion of ERLOD within the framework of clinical research would include considerations of justice and fairness. However, this is beyond the scope (and page limit) of this case analysis. Should you be interested in reading this section, please contact the author.

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