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# ENSURING THE GIFT OF LIFE: 'NON-NEAR RELATIVES' AS ORGAN DONORS UNDER TRANSPLANTATION OF HUMAN ORGANS & TISSUES ACT

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#### **Abstract**

With the advancement in the field of medical science came the boon of organ transplantation, ensuring that several lives could be saved. However, this scientific breakthrough brings with it the possibility of gross exploitation of economically backward classes through organ trade. In India, to regulate the transplantation of organs while maintaining a balance between saving lives and ensuring organ trafficking is not taking place, the issue was addressed in the Transplantation of Human Organs and Tissues Act (THOTA). This article explores the complicated web of moral, medical, and legal issues surrounding organ donation. The study starts out by explaining THOTA and its legislative goals. The regulations relating to non-near relative donations are then carefully examined, taking into account the advantages, precautions, and difficulties of establishing the veracity of the donor-recipient relationship. The article also investigates the implications of THOTA on the right to life and looks at various legal viewpoints on the subject. Comparison has been made with Iranian law, which allows living, unrelated kidney donors in exchange for remuneration. The article's analysis of various legal interpretations, which serves as its conclusion, sheds insight on the delicate balance between medical progress and ethical considerations in the field of organ transplantation.

#### Introduction

In the realm of medical advancements and compassionate acts of humanity, the field of organ transplantation stands as a testament to both science and altruism. Organ transplantation has the power to bestow the gift of life upon those grappling with life-threatening conditions, offering a glimmer of hope and the promise of a healthier future.<sup>2</sup> However, within the noble

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<sup>&</sup>lt;sup>2</sup> Transplantation of Human Organs and Tissues Act (THOTA), National Organ Transplant Program (NOTP) including NOTTO/ROTTOs/SOTTOs (July, 16. 2020). https://dghs.gov.in/WriteReadData/userfiles/file/RTI/THOA NOTP NOTTO ROTTO SOTTO 16-7-2020.pdf.

act of organ donation exists a complex interplay of ethical considerations, medical limitations, and legal regulations.

Suppose a 59-year-old individual battling a dire medical predicament, demands an urgent kidney transplant for his survival. Unfortunately, none of his immediate family members possess the requisite medical fitness to serve as organ donors. However, on the horizon lies a potential solution: a distant, financially disadvantaged cousin who is medically fit to donate a kidney. While this prospect could be seen as a source of hope and relief, it also raises concerns about the potential for exploitation in the organ transplantation process.

In this submission, the authors have discussed the enactment of the beneficial legislation known as the Transplantation of Human Organs and Tissues Act (THOTA) and the legislative intent behind it. The authors have then analysed the provision related to the donation of organs by non-near relatives, exploring its benefits, the safeguards in place to prevent misuse, and the challenges associated with ascertaining the bond of affection between the donor and recipient. Next, the authors have scrutinized the scope of THOTA in relation to the right to life and examined the judicial stance on this matter. Additionally, the authors have provided insights into Iranian law governing living unrelated renal donation, which permits organ donation in lieu of compensation. Finally, the authors have concluded the article with remarks concerning the interpretation of the law in light of all the points presented.

### The 'Beneficial Intent' Behind the Enactment

Organ transplantation is a selfless act motivated by the desire to save lives, but it also has a dual nature. On the one hand, it highlights our capacity for *altruistic* deeds and symbolises the highest level of human compassion. However, it can also provide a favourable environment for *exploitation*, particularly when weaker groups of society are placed in a desperate situation and have little ability to defend their own interests.

In recognition of this intricate balance between compassion and exploitation, THOTA came into being in 1994. This legislation was conceived with a dual purpose: *first*, to regulate the process of organ and tissue transplants, and *second*, to combat the burgeoning commercialization of organ trade.<sup>3</sup> It aimed to strike a compromise between the need to save lives by using the existing technology to transplant organs and making sure that the poor were not taken advantage of by the rich in this procedure, as was primarily feared at the time.

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<sup>&</sup>lt;sup>3</sup> Statement of Objects and Reasons, The Transplantation of Human Organs and Tissues Act, 1994.

Subsequently, THOTA underwent amendments in 2011, with the latest set of rules dating back to 2014, seeking to enhance its efficacy and relevance.

# The Provision for "Non-Near Relatives" under THOTA

With a primary focus on *near relatives* as potential donors for people in need, THOTA presents a methodical approach to organ and tissue donation. In the 1994 version of the law, *near relatives* had a fairly narrow definition. Notably, in 2014, the term of *near relatives* was broadened to include grandparents and grandchildren, increasing the pool of potential family donors.<sup>4</sup>

However, because THOTA is a welfare-oriented legislation, it cannot overlook the situation of patients whose close relatives are unable to give organs due to physical or mental ailments. As a result, Section 9(3) of THOTA permits *non-near relatives* to volunteer as organ donors on the condition that their motivation is founded in true *love and affection* for the sick patient.

The THOTA's inclusion of *non-near relatives* as potential organ donors can greatly increase the pool of organ donors, solving the urgent problem of organ scarcity. This growth is extremely important because it corrects the ongoing organ transplant supply-demand imbalance.

First, allowing non-near relatives to step in as donors when close relatives are unable to do so for medical reasons creates additional opportunities for organ donation. This increases the likelihood of discovering suitable matches for patients on transplant waiting lists in addition to expanding the pool of potential donors.

*Second*, a variety of donor sources, such as distant relatives, can help shorten the waiting periods for patients in need of life-saving transplants. By expanding the donor pool, we can potentially save more lives and alleviate the suffering of those waiting for organs.

Therefore, a provision has been created in the Act to include non-relatives as well as relatives within the scope of donors, furthering the objective of ensuring human *welfare* and *lifesaving*. However, this calls for crystal-clear legislative rules to strike a balance between the rights of sick people in need of organ donation and those of the economically vulnerable group vulnerable to exploitation.

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<sup>&</sup>lt;sup>4</sup> Transplantation of Human Organs (Amendment) Act, 2011 (16 of 2011).

#### Prevention of the Misuse of "Non-Near Relatives"

To address the concern of 'blatant exploitation of poor by the rich' as expressed in number of parliamentary debates was also sought to be prevented by THOTA. The provision related to 'Authorisation Committees' was added in the Act. Several procedural requirements were laid down to ensure that transplantation by *non near relatives* under the act happen only when they are in furtherance of the beneficial object of the act and not for commercial exploitation.

A critical role is played by the *Authorization Committee* in ensuring that no commercial transactions taint the altruistic act of organ donation. The Committee undertakes a comprehensive assessment, considering the nature of the relationship between the donor and recipient, scrutinizing the reasons behind the donation, and diligently examining various factors. This process includes the examination of documentary evidence, review of old photographs, verification of the absence of intermediaries, assessment of the donor's financial status, confirmation of the absence of drug addiction, and interviews with adult family members to ascertain the authenticity and awareness of the decision.

Moreover, Section 13B of THOTA bestows upon the Authorization Committee powers akin to those of a civil court, enabling it to issue summons, request crucial documents, and even issue search warrants. These powers empower the Committee to conduct a meticulous and thorough evaluation, ensuring the authenticity and legitimacy of the organ donation.

As the Authorization Committee grapples with the responsibility of making decisions that can irrevocably shape the future of a recipient, it operates within the ambit of three fundamental principles.<sup>5</sup> *First*, it must conduct a thorough investigation while upholding the principles of natural justice. *Second*, it is tasked with the application of critical judgment to the case at hand, considering the unique circumstances. *Last*, should the Committee decide to reject an application, it is obligated to provide a comprehensive and well-documented rationale for its decision.<sup>6</sup>

In this endeavour, THOTA aligns itself with the principles enshrined in the case of *Bandhua Mukti Morcha v. Union of India*, where the court emphasized the state's obligation to safeguard

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<sup>&</sup>lt;sup>5</sup> Vandana Dixit v. Visitor, Sanjay Gandhi Post-Graduate Institute of Medical Sciences 2010 SCC OnLine All 2660 ¶27.

<sup>&</sup>lt;sup>6</sup> *Id*.

the fundamental rights of vulnerable sections of society and prevent their exploitation, particularly when exacerbated by societal factors.<sup>7</sup>

## Ascertaining the Bond of 'Affection' between the Donor and the Recipient

Establishing an affectionate and attached relationship between the parties is necessary for a non-relative to be eligible to donate organs. A provision like this prevents commercial exploitation from appearing as a donation. However, the Authorisation Committee while determining if a bond of love and affection exists between the donor and recipient has to take a variety of circumstances into account and this can often act as an ordeal.

In the matter of *Parveen Begum v. Appellate Authority*, the petitioner/recipient was advised that the only viable choice for saving her life was to have a kidney transplant. The donor, though not coming under the category of *near relatives*, had a mother-daughter relationship with the recipient and took care of her in her tough times. But, on making an application before the Authorization Committee, it was rejected after conducting a below-par and haphazard inquiry on the following grounds<sup>8</sup>:

*First*, there is no convincing evidence linking the donor with the receiver; *second*, the husband and close family members are unwilling to donate; and *third*, there is income disparity between the two parties.

The Act and the Rules do not seek to prohibit, but to only regulate the transplant of organs and tissues from cadavers and living human beings. What is prohibited is the commercial transaction in the giving and taking of organs and tissues. However, donations offered out of love and affection - even amongst those who are not near relatives, is permitted. The aforesaid scheme under the Act recognizes two of the greatest human virtues of love and sacrifice, and also the fact that such intense love and affection need not necessarily be felt only for one's own blood or spouse, but could also extend to those not so closely related, or for those not related at all.<sup>9</sup>

Since, the Authorization Committee has only focused on the reasons why the recipient's close relatives have refused to give their organs in order to preserve the recipient's life and has not even posed a single inquiry addressing the financial relationship between the beneficiary and

<sup>&</sup>lt;sup>7</sup> Bandhua Mukti Morcha v. Union of India (1984) 3 SCC 161.

<sup>&</sup>lt;sup>8</sup> Parveen Begum v. Appellate Authority, 2012 SCC OnLine Del 2839. ¶8

<sup>9</sup> Id.

the donor. The transplant cannot be delayed just because there may be a financial connection without any supporting evidence. People who are either distantly related or unrelated in any way frequently become closer friends because of their shared interests or through a strange twist of fate than even their own parents, siblings, or children.<sup>10</sup>

In the Manoranjan Rout v. State of Orissa case, we come across a compelling situation where the petitioner, a physician with renal failure, was in need of an urgent kidney transplant due to a life-threatening predicament. The only real chance for saving his life, according to the Hospital medical staff, was a kidney transplant.<sup>11</sup>

The petitioner actively looked for a suitable kidney donor within his extended family because his wife and other family members' blood types did not match. Ultimately, petitioner No. 2, who is the son of petitioner No. 1's father's sister, consented to donate a kidney, creating a matching donor-recipient pair. However, the Authorization Committee declined to consider their request.

In light of petitioner No. 1's declining health, the petitioner claimed that the Committee had improperly considered their application. As a result, they petitioned the court for intervention under Article 226 of the Indian Constitution. The court acknowledged that in situations where donors and recipients are familiar to one another through shared family ties and visits, approvals should be given on the basis of pure love, affection, and humanitarian considerations.

This case highlights the necessity for sensitive and adaptable policies regarding organ transplantation. It reaffirms the notion that non-near relatives should not be denied the opportunity to donate organs when there is a demonstrable tie of love and care, especially in cases where life is at risk, like the one petitioner No. 1 encountered. Such situations necessitate a nuanced appreciation of the human element of organ donation, which goes beyond rigid notions of familial ties in order to save lives.

In the case of *Balbir Singh v Authorization Committee*, we are presented with a scenario in which the petitioner, Balbir Singh, had a condition, called cirrhosis of the liver caused by hepatitis C, that required immediate liver transplantation. Baljit Singh, his brother, offered himself as a willing donor to help save his brother's life. The HLA Typing Test first failed to

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<sup>&</sup>lt;sup>10</sup> Id. ¶68.

<sup>&</sup>lt;sup>11</sup> Manoranjan Rout v. state of Orissa ¶2.

prove a close connection between the petitioner and the donor, which raised questions about the donor's eligibility under the laws in effect.<sup>12</sup>

It is crucial to note that this instance highlights the necessity of reconsidering the rigid criteria of a *near relative* in organ transplant cases, especially when the recipient's life is hanging by a thread. The court acknowledged that, in contrast to kidney transplants, where tissue matching is crucial, liver transplants primarily depend on variables such matching the size and condition of the organ and blood group compatibility. These medical factors, which are independent of any particular definition of a *near relative*, are crucial to the transplant's success.<sup>13</sup>

The court noted that the requirement that the donor be a *near relative* in this case lacked any medical or scientific foundation due to the petitioner's deteriorating health and the urgent need for a liver transplant. This example demonstrates how current laws should change to reflect the practicalities of organ donation in medicine, emphasising that non-relatives shouldn't be prevented from giving organs when their compatibility is confirmed by medical evaluations such size and blood group matching. In the end, saving lives should take precedence over rigid conceptions of family bonds.

In the matter of *Huma Qamar and Anr. v. Authorization Committee*, the petitioners made a strong argument on their behalf. Petitioner No. 1 had End Stage Renal Disease (ESRD), and as a result of renal failure, she was totally reliant on dialysis twice a week. <sup>14</sup> Petitioner No. 2, who had known Petitioner No. 1 for more than ten years and shared a bond similar to that of siblings, voluntarily offered to donate her kidney in this dire medical situation out of love and devotion.

Medical experts confirmed this connection, attesting to the voluntariness of petitioner no. 2's choice and the absence of outside influences. Despite this, the Authorization Committee, in its decision, rejected the organ transplantation application on grounds that long association and love and affection could not be established, citing differences in community, age, and economic status between the donor and recipient.<sup>15</sup>

The petitioners correctly contended that the rejection was not warranted because there was no proof that any money was exchanged, threats were made, or coercion was used to make the judgement. The true respect and devotion that had grown over the years between petitioners

<sup>&</sup>lt;sup>12</sup> Balbir Singh v Authorization Committee ¶ 3.

<sup>&</sup>lt;sup>13</sup> *Id*. ¶ 5.

<sup>&</sup>lt;sup>14</sup> Smt. Huma Qamar and Anr. V Authorization Committee ¶6

<sup>15</sup> Id. ¶12

No. 1 and 2 was judged to be irrelevant to the Committee's focus on the disparity in communities and ages.<sup>16</sup>

This case highlights the importance of considering ties based on love and affection, even those that are not strictly defined by traditional familial or social bounds, when determining a donor's appropriateness. When a person's life is in danger, the priority should be saving lives through organ donation, taking into account the sincere feelings and connections that exist between potential donors and receivers.

In the case of Arup Kumar Das v. State of Orissa, the petitioner, a 28-year-old attorney with kidney failure, was urged to get a kidney transplant by medical professionals. <sup>17</sup> However, the Authorization Committee turned down the petitioner's request, citing a number of factors, such as the donor and recipient's alleged lack of emotional attachment, their brief acquaintanceship of only two years, and inadequate HLA matching.

The court acknowledged that the THOTA had been in place for more than 16 years but pointed out that the goals of the Act were not being sufficiently met.

To address this matter, the court issued orders stressing that the lack of HLA compatibility should not be the only factor used to reject approval for kidney transplantation in situations involving a single unrelated donor and recipient combination. Due to the urgency and seriousness of the petitioner's medical situation, the court's ruling aimed to encourage equitable access to organ transplantation.

The Authorization Committee's quasi-judicial role was also emphasised by the court, underscoring the significance of adhering to natural justice principles when conducting business. In order to make sure that consent for transplantation is granted voluntarily and not as a result of undue influence or coercion, it was emphasised the importance of carefully inspecting donors and recipients during investigations.<sup>18</sup>

In order to uphold the principles of justice and compassion in the context of organ transplantation, it is crucial to strike a balance between regulatory measures and ensuring that people who are in urgent need of organ transplants are not unduly constrained by onerous requirements.

<sup>&</sup>lt;sup>17</sup> Arup Kumar Das v State of Orissa ¶2

There is little doubt that the Authorization Committee has a quasi-judicial role and, as such, is required to follow processes that are reasonable and consistent with natural justice principles. <sup>19</sup> It is possible to identify any signs of suspect circumstances during the inquiry procedure as the donor and recipient are examined by the Authorization Committee. The Authorization Committee will examine the donor and recipient during the inquiry process in order to look for any signs of suspicious circumstances. It is only reasonable to claim that the authorization cannot be considered to have been given voluntarily unless all such doubtful circumstances are effectively addressed and eliminated. Authorization shouldn't be granted merely because of the donor's love or devotion to the recipient, or for any other unusual circumstances; rather, it should be the outcome of a fair and complete evaluation. <sup>20</sup>

## Interpretation of THOTA in light of the 'Right to Life'

As said by HH Pope Francis and WHO Director-General, Dr Tedros Adhanom Ghebreyesus, "Healthcare is a right, not a privilege. It is the duty of governments to ensure its provision to all citizens". A man cannot be compelled to limit his life to simply his animalistic perceptions and pleasures in a well-functioning society. Man is able to create societies that are conducive to growth and intellectual enjoyment. The latter pleasure can only be fostered in an environment where he is able to freely devote himself to his mind rather than worrying about the limitations that impede his growth.

Any civilised society's guarantee of the right to life includes the rights to housing, food, water, a clean environment, education, and medical treatment. Any civilised culture is aware of these fundamental human rights.<sup>22</sup> It is a settled position of law that the right to health comes under the right to life under Article 21 and thus, the government is under a constitutional obligation to provide the patient with medical facilities.<sup>23</sup>

In the case of S Samson v Authorization Committee<sup>24</sup>, the recipient underwent regular dialysis because of chronic renal failure. As the recipient's family members were either physically unsuitable or legally too young to donate a kidney, he approached the donor, a non-relative.

<sup>&</sup>lt;sup>19</sup> *Id* ¶11.

<sup>20</sup> Id

<sup>&</sup>lt;sup>21</sup> World Health Organisation, 'HH Pope Francis and WHO Director-General: Health is a right and not a privilege', News release (Oct. 23, 2018) https://www.who.int/news/item/23-10-2018-hh-pope-francis-and-who-director-general-health-is-a-right-and-not-a-privilege.

<sup>&</sup>lt;sup>22</sup> Chameli Singh v. State of U.P., (1996) 2 SCC 549.

<sup>&</sup>lt;sup>23</sup> State of Punjab v. Mohinder Singh Chawla, (1997) 2 SCC 83.

<sup>&</sup>lt;sup>24</sup> S. Samson v. Authorization Committee for Implementation of Human Organ Transplantation, 2008 SCC OnLine Mad 317.

The application was turned down by the Authorization Committee because the recipient had only known the donor for two years and there was a chance that money would be exchanged to make the transplant possible. By using its writ jurisdiction, the court issued the writ of certiorari, overturning the Committee's decision. It further ruled that the Committee must conduct the investigation with the goal of saving a life, therefore the inquiry must be fair and expeditious.<sup>25</sup>

In another case of *Vandana Dixit v. Visitor*; *Sanjay Gandhi Post-Graduate Institute of Medical Sciences*, the recipient had experienced renal failure, and she was becoming worse every day. Despite their willingness, none of the recipient's close relatives could donate an organ due to medical restrictions. Because of his deep love for the receiver, the donor, a non-near relative, voluntarily volunteered his kidney for donation. Despite the Authorization Committee allowing the transplant to go-ahead, the concerned hospitals were impeding it, endangering the patient's right to life. The court agreed with the petitioners' arguments, stating that "right to life includes protection of health and health care" and that since the hospital is not only engaging in commercial activity or business for the purpose of making enormous profits but also in social service and is required to provide right, effective, and prompt medical treatment and health care like any other Government Hospital, it cannot be construed as violating the letter and spirit of Article 21 of the Constitution.<sup>26</sup> Furthermore, delaying such care might occasionally prove fatal for the ill person, who has a right to enjoy a longer, more comfortable life. No human organ transplant can be rejected for grounds not covered by the Act.<sup>27</sup>

In another case of *Vidya Ramesh Chand Shah vs. State of Gujarat*, the petitioner raises a fundamental concern regarding the Indian Constitution's Article 21's protection of the right to life in the context of rules governing organ transplantation. At the core of the issue are Section 9 and Rule 7 of the Transplantation Rules, which state that transplantation should not be allowed if the recipient is a foreign country and the donor is an Indian national unless they are close relatives.<sup>28</sup>

The petitioner claims that these regulations violate Articles 14 and 21's fundamental rights because they place unjustifiable limitations on the right to life and health by restricting access

<sup>&</sup>lt;sup>25</sup> Id. ¶11

<sup>&</sup>lt;sup>26</sup> Vandana Dixit v. Visitor, Sanjay Gandhi Post-Graduate Institute of Medical Sciences 2010 SCC OnLine All 2660.

<sup>27</sup> Id

<sup>&</sup>lt;sup>28</sup> The Transplantation of Human Organs and Tissues Rules, 2014

to organ transplants based on nationality and kinship.<sup>29</sup> The petitioner maintains that people with organ failure, such as kidney and liver disorders, legitimately have the right to request these life-saving transplant procedures without being constrained by these limitations.

Specifically, the requirement for a domicile certificate to be registered as a recipient for cadaveric organ transplants in Gujarat was deemed illegal and unconstitutional by the court in its judgement.<sup>30</sup> The petitioner and others will now be able to get organ transplants without being subject to this restriction thanks to this ruling, which upholds their fundamental right to life and healthcare.<sup>31</sup> The necessity of safeguarding the right to life in the context of organ transplantation laws and providing fair access to life-saving treatments is highlighted by this case.

These three cases highlight that the primary objective of THOTA is to facilitate and enhance the transplantation process, rather than creating unnecessary hurdles, with the ultimate goal of saving lives. The courts have time and again correctly interpreted THOTA and invoked it to support the transplantation process and enable life-saving interventions. These cases could exemplify how the act's provisions were utilized to overcome obstacles or challenges and ensure that the recipient receives timely and appropriate treatment.

#### **Iranian Law on Kidney Transplantation**

Many countries have strictly prohibited the donation of organs by people who are not genetically related to the recipient. This approach mainly shows the intent of the counties to curb the menace of organ trafficking and commercial exploitation of the poor.

However, some countries like Iran have formally adopted laws to allow for donation or organs by non-related parties even for consideration. While this may seem to be ethically in conflict with the altruistic objectives of laws regulating transplantation of organs, their reasoning for having such provisions in place is sound.

The Iranian law on living unrelated renal donation has safeguards in place to ensure that there is no coercion on the donor to donate organs. Some scholars are of the opinion that disallowing organ donation in lieu of payment on the ground that it is unethical is a form of state paternalism.<sup>32</sup>

31 Id ¶46

<sup>&</sup>lt;sup>29</sup> Vidya Ramesh Chand Shah v. State Of Gujarat AIR 2009 Guj 7 ¶17

<sup>&</sup>lt;sup>30</sup> Id ¶45

<sup>&</sup>lt;sup>32</sup> Friedman EA, Friedman AL. 'Payment for donor kidneys: pros and cons.' Kidney Int 2006; 69: 960–962.

As long as steps are taken to ensure that there is no coercion on donors to donate their organs, they should not be deprived of choosing this option to not only improve their economic situation but also save lives.

And contrary to the common belief that exploitation is bound to happen when organ transplantation is allowed in exchange for monetary consideration,<sup>33</sup> studies conducted in Iran have shown that the disparity in the socio-economic status of the donors and the recipient is not that high. The recipients don't always have a clear superiority over the average donor as is feared by ethicists.

#### Conclusion

Permitting non-near relatives to donate organs with authorization from the committee enhances the overall organ procurement ecosystem, offering hope to patients who might otherwise face prolonged waits or even adverse health outcomes.

In this evolving landscape of organ transplantation, the law must adapt to accommodate the motivations behind these selfless acts. It is a testament to the resilience of the human spirit and the deep-seated compassion that transcends the boundaries of self-interest. As we move forward, striking a balance between regulation and encouragement of altruistic donations remains paramount, ensuring that the gift of life continues to thrive, unfettered by exploitation, and guided by the principles of compassion and humanity.

Although safeguards are necessary to ensure that exploitation of the poor does not take place, transplantation of organs cannot be prohibited. Further, countries like Iran give us a perspective that an alternative to the traditional ethical understanding of the issue of transplantation of organs is possible. The same may even proof to be in the best interest of both doner as well as recipient.

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<sup>&</sup>lt;sup>33</sup> See generally, Zargooshi J. Iranian Kidney Donors: Motivations And Relations With Recipients. J Urol 2001; 165: 386–392.