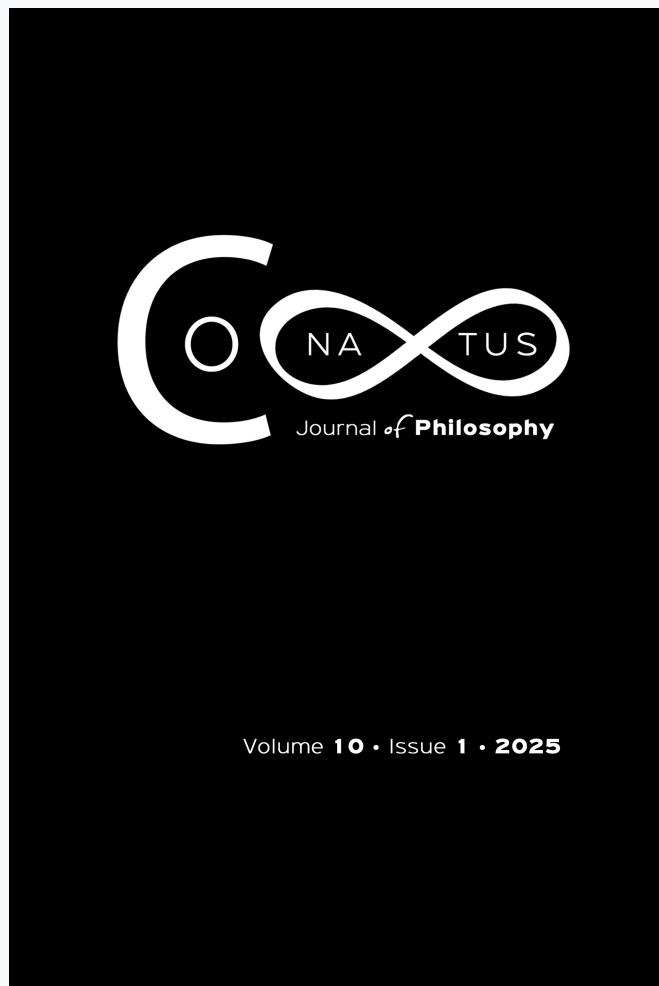


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### Negotiating Autonomy: Lived Experiences of Female Living Organ Donors in Turkey

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# Negotiating Autonomy: Lived Experiences of Female Living Organ Donors in Turkey

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## Abstract

*One of the most significant developments in the field of health in the past century is organ transplantation. While often regarded as a life-saving solution for patients with end-stage organ failure, the lived experiences of living organ donors – especially women – remain underexplored in the literature. This study, conducted between 2022 and 2024, employed qualitative methods and a feminist phenomenological design. The study examines how socio-cultural expectations, kinship obligations, and internalized gender norms intersect to influence women's decision-making processes in living organ donation. Among living donors, those who donate a liver or a kidney take on significant physical and psychological risks, making their perspectives particularly important for ethical reflection. Based on interviews with 18 female donors in Turkey, the findings reveal how women's lived experiences of donation are shaped by their embodied vulnerability, relational roles, and the moral weight of familial obligation. Rather than autonomous acts made in isolation, these decisions emerge within gendered landscapes marked by asymmetrical power dynamics and cultural expectations. By attending to how women articulate their experiences of bodily sacrifice, risk, and post-donation subjectivity, this phenomenological inquiry highlights the necessity of integrating a gender-sensitive lens into bioethical discourse – one that recognizes how normative frameworks and structural inequalities shape and constrain women's autonomy in living organ donation.*

**Keywords:** *lived experience; autonomy; organ transplantation; living organ donor; Turkey*

## I. Introduction

**I**n the 21<sup>st</sup> century, with the almost complete authority of medicine over the biological body, death is being challenged, reshaping the meanings of concepts such as ethics, body, life, and death.<sup>1</sup>

<sup>1</sup> Philippe Ariès, *The Hour of Our Death* (Oxford University Press, 1981); see also Roberto Andorno and George Boulas, "Global Bioethics in the Post-Coronavirus Era: A Discussion with Roberto Andorno," *Conatus – Journal of Philosophy* 7, no. 1 (2022): 185-200.

Changing living conditions reveal different disease models and offer new treatment methods.<sup>2</sup> Organ transplantation, one of the most remarkable applications in medicine, changed the body's fate and included it in an endless project. One of the ongoing challenges in organ transplantation is the scarcity of resources, particularly cadaveric donors, prompting some countries to promote living organ donation and explore alternative methods such as utilizing anencephalic newborns as donors<sup>3</sup> and investigating xenotransplantation.

This advancement in medicine does not affect men and women equally. Gender inequalities observed in various aspects of social life are also reflected in organ transplantation practices.<sup>4</sup> Gender has a considerable impact on donor availability, access to services,<sup>5</sup> medical biases, and post-transplant care responsibilities,<sup>6</sup> all of which are influenced by cultural norms and gender. The prevailing masculine hierarchy within medicine, coupled with the historical normalization of the male body as the standard, along with the underrepresentation of women in medical research (exemplified by the lack of focus on issues like breast cancer),<sup>7</sup> perpetuates the notion of women as potential donors. Femi-

<sup>2</sup> Zeljko Kaludjerovic, "Bioethics and Hereditary Genetic Modifications," *Conatus – Journal of Philosophy* 3, no. 1 (2019): 31-44.

<sup>3</sup> Charles N. Rock, "The Living Dead: Anencephaly and Organ Donation," *NYLS Journal of Human Rights* 7, no. 1 (1989): 243-277.

<sup>4</sup> Annika Gompers et al., "Intersectional Race and Gender Disparities in Kidney Transplant Access in the United States: A Scoping Review," *BMC Nephrol* 25, no. 1. (2024): 36; Sanskriti Chauhan et al., "Nationwide Data on Gender Disparity in Solid Organ Transplantation for India in the Pre-pandemic and Pandemic Era," *Transplantation* 6, no. 9 (2022): 230; Amelie Kurnikowski et al., "Country-specific Sex Disparities in Living Kidney Donation," *Nephrology, Dialysis, Transplantation* 37, no. 3 (2022): 595-598; Michael Darden et al., "Persistent Sex Disparity in Liver Transplantation Rates," *Surgery* 169, no. 3 (2021): 694-699; Javeria Peracha et al., "Gender Disparity in Living-Donor Kidney Transplant Among Minority Ethnic Groups," *Experimental and Clinical Transplantation* 14, no. 2 (2016): 139-145; Cecilia M. Øien et al., "Gender Imbalance among Donors in Living Kidney Transplantation: The Norwegian Experience," *Nephrology Dialysis Transplantation* 20, no. 4 (2005): 783-789; Anette Melk et al., "Sex Disparities in Dialysis Initiation, Access to Waitlist, Transplantation and Transplant Outcome in German Patients With Renal Disease – A Population-Based Analysis," *PLoS ONE* 15, no. 11 (2020): e0241556; Ravikiran S. Karnam et al., "Sex Disparity in Liver Transplant and Access to Living Donation," *JAMA Surgery* 156, no. 11 (2021): 1010-1017; Francesca Puoti et al., "Organ Transplantation and Gender Differences: A Paradigmatic Example of Intertwining Between Biological and Sociocultural Determinants," *Biology of Sex Differences* 7, no. 1 (2016): 35.

<sup>5</sup> Jessica B. Rubin et al., "Organ Transplantation and Gender Differences: A Paradigmatic Example of Intertwining Between Biological and Sociocultural Determinants," *World Journal of Gastroenterology* 25, no. 8 (2019): 980-988.

<sup>6</sup> Ya-Ping Lin, "Visible Body, Invisible Care: Family, Gender Politics, and the Female Caregiver in Living Donor Liver Transplantation in Taiwan," *SSM - Qualitative Research in Health* 4 (2023): 100346.

<sup>7</sup> Janet R. Osuch et al., "A Historical Perspective on Breast Cancer Activism in the United

nist bioethicists delve into issues such as gender discrimination, power dynamics, imbalances/disparity in transplantation processes, and autonomy, whose voices are taken into account and whose are disregarded in transplantation decisions. They also explore how medical practices intersect with societal norms.<sup>8</sup> The primary objective of the study is to comprehend and interpret women's decision-making experiences of living organ donation in Turkey within the context of gender.

Living organ transplantation depends on some bodies giving up their organs to provide treatment for others. While this renunciation is justified in low-income countries as a nation-specific example of self-sacrifice,<sup>9</sup> it is important who will risk their body and life through organ donation, and who will benefit from this risk. When examining living organ transplants, it becomes evident that women are more frequently at risk.<sup>10</sup> In traditional patriarchal societies, mothers, sisters, and wives are expected to make sacrifices<sup>11</sup> for their country, family, and children and give up their bodies. Thus, both gender and autonomy emerge as important variables in organ transplantation as well as other inequalities in the field of health. The existing gender gap in organ transplantation underscores the need to explore the multifaceted gender perspectives within the context of organ transplantation.<sup>12</sup> Research has consistently revealed significant gender disparities among both organ recipients and donors, underscoring a pressing issue that warrants further investigation. Additionally, numerous studies have substantiated the presence of substantial socio-ethical and biological implications surrounding organ donation, particularly within the framework of gender dynamics. These observed disparities prompt crucial inquiries into individual autonomy and the ethical considerations inherent in organ transplantation.

This qualitative study was conducted in Turkey between 2022 and 2024, employing a phenomenological design. It is important to note

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States: From Education and Support to Partnership in Scientific Research," *Journal of Women's Health* 21, no. 3 (2012): 355-362.

<sup>8</sup> See Darija Rupčić Kelam and Ivica Kelam, "Care and Empathy as a Crucial Quality for Social Change," *Conatus – Journal of Philosophy* 7, no. 2 (2022): 157-172.

<sup>9</sup> Megan Crowley-Matoka, *Domesticating Organ Transplant: Familial Sacrifice and National Aspiration in Mexico* (Duke University Press, 2016).

<sup>10</sup> Wendy A. Rogers et al., eds., *The Routledge Handbook of Feminist Bioethics* (Routledge, 2022); Laura Rota-Musoll et al., "An Intersectional Gender Analysis in Kidney Transplantation: Women Who Donate a Kidney," *BMC Nephrology* 22, no. 1 (2021): 59-69.

<sup>11</sup> Ann Mongoven, "Sharing Our Body and Blood: Organ Donation and Feminist Critiques of Sacrifice," *The Journal of Medicine and Philosophy* 28 no. 1 (2003): 89-114.

<sup>12</sup> Vivek Kute et al., "Act Together and Act Now to Overcome Gender Disparity in Organ Transplantation," *Experimental and Clinical Transplantation* 22, no. 1 (2024): 17-27.

that the act of contemplating donation and the experience of actual donation are two distinct phenomena. Data were collected through in-depth interviews with a purposive sample of 18 women aged 18-55 who volunteered for kidney and liver donation. The names of the interviewees were coded and changed. The participants were voluntary female donors from various hospitals in Turkey over the past decade. The youngest of the women interviewed was 22, and the oldest was 70 years old. When they became donors, the youngest was 18, and the oldest was 47 years old. 4 kidney and 14 liver donors were interviewed. The study examines the experiences of women voluntarily donating their liver and kidneys within the context of gender, utilizing descriptive analysis. The data were analyzed thematically, focusing on themes such as family relationships, patriarchal structures, criticism of disclosure, and altruism, which influence women's autonomy in living organ donation decisions. The study integrated feminist theory and the concept of autonomy to interpret these experiences. The unique perspective of women in a phenomenological study with feminist concerns is a powerful counter to all tendencies that objectify the body. Through feminist phenomenology, we can now include the experiences of women who have undergone living organ donation, allowing them to express their experiences in their own words. This unique perspective is chosen to highlight the criticism that, in organ transplantation practices, while there is ample emphasis on treatments, medical terms, and narratives, as well as the comments of renowned doctors performing numerous transplants each year, the experiences and perspectives of patients and donors are often overlooked.

## II. Gendered autonomy in living organ donation

It's not just medical advancements that make organ transplantation possible, but also autonomy and consent procedures. Autonomy in medicine can be defined as the principle whereby individuals possess the ability and right to make their own decisions, emphasizing their freedom to make informed choices regarding their treatments and healthcare situations. With this signature, the medicine authority legally waives all medical operation responsibilities. This consent is obtained by filling out and signing a consent form. While the decision to participate in organ donation is often perceived as a personal choice, it is a socially influenced decision shaped by factors such as societal gender expectations as sacrifice culture, norms of selflessness, altruism, body control policies, family and community expectations (expectations of caregiving and nurturing), perceptions of risk and safety,

healthcare decision-making dynamics, religious and cultural beliefs, economic considerations, educational attainment and awareness, legal and ethical considerations. Feminist autonomy theories delve deep into how internalized and external oppression influence an individual's overall and specific autonomy.<sup>13</sup> There is no consensus as to which theoretical position is correct. Nevertheless, there is a substantial body of evidence to suggest that oppressive socialization and oppressive practices have a detrimental impact on autonomy, potentially leading to its complete erosion. We need to thoroughly explore the practice of living organ transplantation to support feminist autonomy theories, which aim to empower women to make independent choices about their bodies and health. Otherwise, it would not be an exaggeration to claim that in the years to come, we will have a worldwide population of women with one kidney and the health problems experienced by these women. This study does not aim at a discussion on Feminist autonomy theories, but to contribute to Feminist autonomy theories by including women's experiences and their interpretations of autonomy, which is of central importance in living organ transplantation practices as a specific example.<sup>14</sup> In particular, relational autonomy, claimed to be self-determination is inherently social, and "the ethics of care" put forward by Gilligan<sup>15</sup> may effectively guide the debate.

Autonomy is the pursuit of personal independence and the desire for dialogue and negotiation with others. However, in the context of gender inequalities, autonomy often intersects with societal expectations and power dynamics, particularly concerning the female body.<sup>16</sup> Understanding autonomy in living organ donation involves recognizing the interplay of medical advancements, consent procedures, and societal influences, especially those related to gender. Feminist autonomy theories emphasize how societal expectations and oppressive practices can undermine individuals' autonomy.<sup>17</sup> While there may be differing

<sup>13</sup> See Andrea Ellner, "Ethics of Conflict, Violence and Peace – Just War and a Feminist Ethic of Care," *Conatus – Journal of Philosophy* 8, no. 2 (2023), 147-173.

<sup>14</sup> Natalie Stoljar, "Feminist Perspectives on Autonomy," *The Stanford Encyclopedia of Philosophy* (Summer 2024 Edition), eds. Edward N. Zalta and Uri Nodelman, <https://plato.stanford.edu/archives/sum2024/entries/feminism-autonomy/>.

<sup>15</sup> Carol Gilligan, *In a Different Voice: Psychological Theory and Women's Development* (Harvard University Press, 1993).

<sup>16</sup> For a very interesting account of how autonomy intersects with societal dynamics in another cultural environment, see Dung Van Vo, "Four Important Characteristics of Women in Confucianism and Its Contribution to the Implementation of Gender Equality in Vietnam," *Conatus – Journal of Philosophy* 9, no. 2 (2024): 283-302.

<sup>17</sup> Andrea Veltman and Mark Piper, eds., *Autonomy, Oppression, and Gender, Studies in Feminist*

theoretical positions, evidence suggests that oppressive socialization can significantly impact autonomy, potentially eroding it completely. Therefore, it is essential to further explore living organ transplantation practices from a feminist perspective, considering power dynamics, consent processes, application differences, transparency of gender data,<sup>18</sup> and long-term effects.

### III. Results

The analysis identified four key factors shaping autonomy in living organ donation decisions. Family relationships (constructed expectations to be accepted, cared for, and self-understanding, particularly in the context of motherhood, where the societal expectation of a mother's selflessness influences the decision to donate) emerged as pivotal, influencing donors' sense of obligation and support. Paternalistic attitudes in healthcare settings often constrain donors' decision-making agencies. Criticism of disclosure highlighted donors' challenges in navigating medical information. Altruism played a significant role, intertwining personal sacrifice with moral duty and normalization of the process.<sup>19</sup>

### IV. Relationships

The family structure in Turkey has implications beyond affection and mediates women's pursuit of self-assurance, expression, and need for acceptance. Women's acceptance of organ donation seems to be influenced by the need to repair relations and gain acceptance within family relationships. The interviews indicate that the family is a contentious environment.

The most thought-provoking finding concerning autonomy is that some women hope to gain power and advantage in this critical situation. Their longing to take full control of their lives has been a motivating factor. One interviewee highlights how she escaped discrimination

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*Philosophy* (Oxford Academic, 2014).

<sup>18</sup> Despite the Global Observatory on Organ Donation and Transplantation (GODT) being the preeminent repository of international data on donation and transplantation rates, gender data was not included until 2017. This information is now available for the first time in the GODT's 2017 annual report.

<sup>19</sup> Especially on the notion of *effective altruism*, see Iraklis Ioannidis, "Shackling the Poor, or Effective Altruism: A Critique of the Philosophical Foundation of Effective Altruism," *Conatus – Journal of Philosophy* 5, no. 2 (2020): 25-46. See also Julian Savulescu and Evangelos D. Protopapadakis, "'Ethical Minefields' and the Voice of Common Sense: A Discussion with Julian Savulescu," *Conatus – Journal of Philosophy* 4, no. 1 (2019): 125-133.

experienced as a girl within her family by becoming a live organ donor. Nergiz stated, “For example, men were always in the foreground in our family. My inability to study was due to the idea that girls don’t study. I just finished my new school, that is, I studied externally. When my family saw my willingness to be a donor, they wondered why we didn’t do it earlier or didn’t allow it. For example, I am currently going through a divorce process. If I had said this five years ago, they would have opposed it, saying it would never happen. But now they don’t think that way; they say we’re behind you in every decision you make. They say you’re strong, you can do it, so it’s something much different than before. There used to be a distinction between girls and boys in the family. But not anymore. It’s like nothing happened after my surgery.”

Offering her life as a bargaining chip to gain approval and acceptance from her family, she takes the risk of becoming a living organ donor for her father. She emphasizes that she has empowered herself by making a significant sacrifice and gained control over her life. The women decided voluntarily, deliberately, and without pressure, but this decision resulted from specific calculations and comparisons, suggesting that the influence of gender cannot be denied in decision-making.

The women interviewed felt that they needed to make more effort than men to gain respect and affection from society. This situation aligns with Beauvoir’s construction<sup>20</sup> of “absolute otherness.” Sinem summarized the situation by saying, “I always tried to make people love me. I always gave of myself because I thought they wouldn’t love me if I didn’t give; I always made concessions.” Through such sacrifices, women strive to prove they are strong, brave, and valuable. However, this effort is often ignored or not sufficiently appreciated after transplantation, which can lead to both emotional and physical injuries for women in the context of organ donation. Fourteen of the respondents are receiving psychological support, mostly in the form of medication. Studies underscore the urgent need for increased support and care for living donors who often face severe psychiatric challenges.<sup>21</sup> The pre-transplant screening of organ donor candidates identifies psychosocial contraindications: “The donor candidate should be under pressure, any untreated psychiatric disorder that may affect decision making, active drug, substance or alcohol addiction, high suspicion of secondary gain, and the candidate should refuse to give written con-

<sup>20</sup> Simone de Beauvoir, *The Second Sex* (Vintage Classics, 2015).

<sup>21</sup> James F. Trotter et al., “Severe Psychiatric Problems in Right Hepatic Lobe Donors for Living Donor Liver Transplantation,” *Transplantation* 83, no. 11 (2007): 1506-1508.

sent or be unable to give consent.”<sup>22</sup> Some of the women interviewed shared that they had previously received psychological treatment, medication or therapeutic support. However, this was not enough to prevent their consent. The women also noted that the drug treatments were intensified after the transplant for reasons such as the fact that the issue was not discussed in the family after the transplant because it did not burden the recipient and because the donor’s sacrifice was not appreciated much. This highlights the pressing need for post-transplant support and care for these individuals.

Nine of the participants were married and had children when they became donors. Despite their status as mothers, they positioned themselves as children and daughters when they decided to become donors. Women’s re-evaluation of themselves as children in their perception of identity made the status of donors possible. In her work, *The Second Sex*, Simone de Beauvoir analyses the reasons for the infantilization and dependence of women by society.<sup>23</sup> She analyses how women are socialized from childhood and how this process renders them dependent. In this context, she focuses on positioning women as the “other” and preventing their full maturation as individuals. The decision to become an organ donor is influenced by the fact that women tend to see themselves as their parents’ children first and foremost. This supports Beauvoir’s view; also Nancy Chodorow’s *The Reproduction of Mothering* examines how women’s relationships with their mothers shape their identities and how they develop a childish dependence and passivity in this process.<sup>24</sup> Chodorow argues that women’s close bonds with their mothers cause them to feel like children in adulthood and, therefore, assume dependent roles. This theory can explain women’s positioning of themselves as children when they decide to become organ donors. However, at the same time, this action also points to a step that women choose to get rid of in childhood. One interviewee stated, “Our relationship is like I am a mother and she is a child; my mother is not my mother but my child. Psychologically, I don’t have a mother; I don’t have a mother figure that I can consult. I also studied at university with them. When I got married, I left for the first time and went to Istanbul. My mother was so united with me that she could not stay far away from me. In 2014, I settled in Istanbul. Three years later,

<sup>22</sup> K. Keven and S. Aktürk, *Transplantasyona Hazırlık Verici. A. Türkmen (Dü.) Inside, Transplantasyon Nefrolojisi Pratik Uygulama Önerileri* (S. 9-25) (Türk Nefroloji Derneği, 2016).

<sup>23</sup> Beauvoir.

<sup>24</sup> Nancy Chodorow, *The Reproduction of Mothering: Psychoanalysis and the Sociology of Gender* (University of California Press, 1999).

my mother became ill and could not stay away from me that much and preferred to keep a part of me (liver) with her. So she made herself psychologically ill, actually; I guess you could say she took it from me by force. Because she wanted a piece of me to stay with her. So I gave it to her, and I was liberated." While cutting off the organ, she also cuts off the relationship; at this point, the woman exhibits symbolic autonomy. It is possible to see a similar situation in the relationship of another interviewee who did not keep in touch with her mother after the transplant. Sevgi said, "Then I said, 'Girl, you should not do this much to yourself anymore', and I stopped seeing her." Another woman, Hayriye, said, "It's hard being a woman. That's what the environment expects in general! I don't think I've been a good daughter in my own opinion (she thought that was because she'd had three different marriages). I feel like I've let them down. If our parents are alive, we always tend to be good children even when we are 60 years old. But society does that to us."

In the context of autonomy, it has been observed that female donors do not perceive themselves as isolated, independent, autonomous individuals within this network of family relationships. Women are constructed within societal norms as daughters, mothers, homemakers, nurturers, providers of care, and sources of comfort, which naturalizes this social role. This finding supports Gilligan's theory.<sup>25</sup> Therefore, it seems appropriate to reopen the discussion on feminist care ethics<sup>26</sup> within the context of living organ donation. Women who donate organs to their children or other family members are influenced by this societal gender role, positioning themselves in caregiving roles based on the biological assumption of their reproductive capabilities. Piraye was the oldest of the interviewees. Today she is 70 years old. She was 47 years old when she was a kidney donor for his brother. She lost her brother 7 years after the operation. When she told her husband that she would be a kidney donor for her brother, her ex-husband and his family opposed her decision, saying that she would regret it if her children needed it in the future. This approach shows the acceptance of women as organ providers within the family. This situation also points to tensions between the nuclear family and the extended family. Although she stated that she did not give up on her decision by saying;

<sup>25</sup> Gilligan approached the moral development of women differently from men and argued that traditional moral theories did not adequately consider the female experience. While Kohlberg defined the male moral perspective as justice ethics, Gilligan described the moral perspective of women as care ethics.

<sup>26</sup> Nel Noddings, *Starting at Home: Caring and Social Policy* (University of California Press, 2002); Rosemaria Tong, *Feminist Approaches to Bioethics* (Routledge, 1997).

“Then you or your family give it to the children, I will give this one to my brother and the other one to the cats, don’t interfere,” the motivation for giving organs to his brother was that they grew up without a father and she accepted his brother as a father.

Some women said they didn’t love the person who received their donated organ, but they still went ahead with the donation. In three cases, the most significant source of motivation was not love,<sup>27</sup> which is contrary to what we are used to hearing in organ donation calls. Ebru said, “My mum might be the unhappiest person I know. She is a person who does not take care of her health, who does not care about anyone, her husband, her mother, her children, and who looks like that (The mother has cared for a disabled husband for many years and continues to do so). I was thinking that maybe she could say, “Don’t let anyone be a donor for me. I don’t want anything from anyone like this is my life, and I’m going. She’s a person who’s given up on her life. I don’t remember many happy times for my mum. She didn’t do anything when I said I was giving my liver to her. She acted like it was normal.” Nancy Chodorow<sup>28</sup> has particularly analyzed how women internalize maternal roles and how these roles reproduce gender norms. The interviewee seems to be deeply shaken by her mother’s lack of appreciation for her sacrifice, perceiving it as normal, expected behavior. However, it is expected that a mother would not accept a practice that harms and endangers her child’s life to save her own.

## V. Patriarchal structures

It is important in the context of rights to argue that women may not have real autonomy over their bodies due to patriarchal norms.<sup>29</sup> In patriarchal societies, women are often confined to specific roles, which are generally defined as weak or secondary. Within this patriarchal system, women often have to cope with feelings of weakness and vulnerability.<sup>30</sup> One of the interviewees stated, “I was a bit more delicate in the family’s eyes, I guess. No one thought I could be so brave; my cousins told me that. They said they didn’t think I could be so brave. Of course, it has changed. I used to be very afraid of getting tattoos

<sup>27</sup> Kristin Zeiler, “Just Love in Live Organ Donation,” *Medicine, Health Care and Philosophy* 12, no. 3 (2009): 323-331.

<sup>28</sup> Chodorow.

<sup>29</sup> Sylvia Walby, *Theorizing Patriarchy* (Basil Blackwell, 1990).

<sup>30</sup> Iris Marion Young, *On Female Body Experience: “Throwing Like a Girl” and Other Essays* (Oxford University Press, 2005).

or piercings, so I never thought I could do something like this... Then I said, I guess I can do it; there is this power in me." When examined from a gender perspective, women's participation in living organ donation can be considered a challenge to the attributes typically associated with men, such as heroism, bravery, strength, resilience, and determination.

I was able to interview one of the families who participated in a cross-transplant. In this case, two women, whose husbands needed kidney transplants, were tested as potential donors. Since neither was compatible with their own husband, they each donated their kidney to the other woman's husband – saving both men's lives. One of the women who donated her kidney, Zehra, lived in Central Anatolia and faced economic hardships that limited her access to communication tools such as the internet and a telephone. Because of this, she could not be reached for an interview. Additionally, the family who received her kidney chose not to share her contact information. As a result, I was unable to speak with her. However, the woman I interviewed shared the following about Zehra's experience: "We provided financial support, and Zehra came on the bus. During the medical tests, a gynecological issue was discovered, which had to be treated first. Later, we also found out that Zehra couldn't read or write – something she had been too ashamed to reveal. Because of this, all the procedures were initially cancelled. Zehra turned red with embarrassment. Then her husband spoke up: 'Hodja, she can't read or write. She was ashamed to tell you! She can't sign.' So we had to start over again. Zehra later signed the consent form at the notary." A feminist perspective underscores the importance of recognizing and addressing power dynamics in discussions of autonomy, particularly in the context of women's experiences in organ donation.

The study did not find research examining the gender factor in the structuring of ethical committees for living organ transplantation. It observed that there is no targeted gender equality in the composition of committee members from a societal gender perspective, with almost all committees consisting predominantly of men. It becomes inevitable that an ethics committee composed entirely of men will be unable to address the needs of gender inequalities. The fact that Zehra could not be recognized as illiterate after all the tests had been carried out could only have been possible under the impression of a careful and gender-conscious committee. In this way, Zehra would not have travelled all this way, would not have been embarrassed because of her economic status and illiteracy, and would not have been subjected

to a series of tests. As stated in Metin's text,<sup>31</sup> ethics committees are products of pluralistic liberal societies in the West and owe their existence to the bureaucratic institutional structure of modernity. Ethics committees should not be instruments of bureaucratic regulation and control. It should be freed to play a critical role within the institution, to support and develop ethical research and researchers, and given time to discuss and explore difficult ethical issues where they arise.<sup>32</sup> The team is exclusively male. An ethics committee will inevitably be unable to respond to the needs of her.

One of the interviewees, who is the youngest child of a family with five siblings and who had just given birth, stated that the donation process was started at the same time for all five siblings and that the tests were performed at the same time and that the doctor, with a paper in his hand and based on biological data, selected her as the most suitable donor among the candidates and informed everyone. In this context, although all five siblings were compatible donors, the possibility of the donor, who was the youngest sibling selected by the doctor, objecting to the doctor as a medical authority was weakened. As Sherwin states,

The reality is that in a hierarchical society, most patients have much less power than most doctors. As a result, many patients are virtually incapable of making truly 'autonomous' decisions in the presence of doctors.<sup>33</sup>

One interviewee answered the question as follows: Who else in the family could have been a donor besides you to your uncle? Were there other people who volunteered? "My brother, one of his friends, and I went as donors. When the doctors saw them, he said, 'They have a belly; they can't be donors, let's start with you.' When that happened, and I was a match, no one else took the test." Women who are donors have been given organs because there are no volunteers around them other than themselves or because they have been deemed suitable by the hospital, doctors, or ethical committee. In this scenario, it's crucial to carefully consider both paternalism, patriarchal structures, and the doctors' autonomy.<sup>34</sup> Both factors play significant roles in deci-

<sup>31</sup> Sevtap Metin, *Biyo-Tıp Etiği ve Hukuk* (Betim Kitaplığı, 2019).

<sup>32</sup> Paul M. McNeill, "Research Ethics Review and the Bureaucracy," *Monash Bioethics Review* 21, no. 3 (2002): 72-73.

<sup>33</sup> Susan Sherwin, *No Longer Patient: Feminist Ethics and Health Care* (Temple University Press, 1992).

<sup>34</sup> For an enlightening discussion on physicians' autonomy, since it discusses autonomy with

sion-making. A doctor who has been socialized in a patriarchal family structure, where traditional gender roles are the norm, and who subscribes to the view that men subjugate women, or who perceives themselves as the natural choice to spearhead this mission due to their role as a caregiver, will, make their choice in favor of women.

The impact of patriarchal structures on women's autonomy in medical decision-making is significant. Women organ donors face societal and gender dynamics that influence their experiences. Gender-sensitive approaches in ethical decision-making are essential to address the challenges faced by women donors and ensure genuine support and respect for their contributions.

## VI. Criticism of disclosure and informed consent

One of the study's important findings was that the information provided about the operation, future results, and side effects for obtaining consent was insufficient. The expressions used suggest that women lack detailed information on many important issues before undergoing surgery. For example, will the abdominal muscles be cut? Why is the gallbladder removed along with the liver? Are individuals genetically predisposed to kidney or liver diseases? Is there a risk of facing the same problem in the future? How does the process of liver regeneration occur? How many years can one live with a single kidney? What will be the duration of the kidney or liver remaining in the recipient? What are the other treatment alternatives? Which lobe of the liver, right kidney or left kidney will be taken? What are the possible complications during and after surgery? How should nutrition be managed after transplantation? Some questions remain unanswered. Some interviewees have so little information about the transplantation process that one interviewee's statement, "I entered the room and saw something written on the board. It said my name and surname and left kidney. So I learned from the board that my left kidney would be taken," clearly illustrates this situation. Could the validity of consent be questioned if given without adequate knowledge about the subject matter?<sup>35</sup>

It is challenging to gather complete information about the long-term effects on organ donors, as most donors are not followed up regularly after the first year once liver function stabilizes. However, recent studies

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relation to an even more challenging issue, euthanasia, see Jose Luis Guerrero Quiñones, "Physicians' Role in Helping to Die," *Conatus – Journal of Philosophy* 7, no. 1 (2022): 79-101.

<sup>35</sup> Evangelos D. Protopapadakis, "Placebo: Deception and the Notion of Autonomy," in *Thinking in Action*, eds. Evangelos D. Protopapadakis and Georgios Arabatzis, 103-115 (The NKUA Applied Philosophy Research Lab Press, 2018).

have shown a potential link between liver damage and dementia in patients with dementia.<sup>36</sup> Therefore, I would like to raise the question of whether organ donors could also face a long-term risk of developing dementia. Post-operative cognitive dysfunction in living donors for liver transplantation is an area of research.<sup>37</sup> Studies have shown that complications such as pre-eclampsia, hypertension, and proteinuria (the presence of protein in the urine) may be more common among kidney donors. Pre-eclampsia is a serious condition that can cause high blood pressure and organ damage during pregnancy. Some reports show an increased risk of gestational hypertension and pre-eclampsia after kidney donation, based on a comparison of pre and post-donation pregnancies in donors.<sup>38</sup> Additionally, I would like to point out that there is no existing research on the risk of early menopause in living donors.

Due to the nature of positive science, it is necessary to act in the light of available information. Although the long-term health outcomes of donors are not known with current knowledge, donors must be thoroughly and accurately informed about known risks and potential consequences. Consequently, fully informing donors about known risks, uncertainties, and alternatives and conducting regular long-term follow-ups are critical to protecting donors' health and autonomy.<sup>39</sup> This action supports an ethical and safe organ transplantation process.

Feminist scholars emphasize the need to create spaces for dialogue and negotiation that enable women to exercise genuine autonomy over their bodies and healthcare decisions, free from societal pressures and gender inequalities. According to the information obtained from the participants in the study, it has been observed that there are different practices regarding organ transplantation in different hospitals. Worldwide, other studies are showing the existence of different applications.<sup>40</sup> Some hospitals are

<sup>36</sup> Scott Silvey et al., "A Possible Reversible Cause of Cognitive Impairment: Undiagnosed Cirrhosis and Potential Hepatic Encephalopathy in Patients with Dementia," *The American Journal of Medicine* 137, no. 11 (2024): 1082-1087.

<sup>37</sup> Nizamettin Bucak et al., "Postoperative Cognitive Dysfunction in Living Liver Transplant Donors," *Experimental and Clinical Transplantation* 12, no. 1 (2014): 81-85.

<sup>38</sup> Anna Varberg Reisaeter et al., "Pregnancy and Birth After Kidney Donation: The Norwegian Experience," *American Journal of Transplantation* 9, no. 4 (2009): 820-824; Pratik B. Shah et al., "Preeclampsia Risks in Kidney Donors and Recipients," *Current Hypertension Reports* 20, no. 7 (2018): 59; Hassan N. Ibrahim et al., "Pregnancy Outcomes After Kidney Donation," *American Journal of Transplantation* 9, no. 4 (2009): 825-834.

<sup>39</sup> For a seminal discussion on informed consent, its scope and limitations, see Dejan Donev and Denko Skalovski, "Responsibility in the Time of Crisis," *Conatus – Journal of Philosophy* 8, no. 1 (2023): 87-109.

<sup>40</sup> Federica Avorio et al., "Neurological Screening in Elderly Liver Transplantation Candidates: A Single Center Experience," *Neurology International* 14, no. 1 (2022): 245-255.

noted to expedite the process very quickly, leaving insufficient time for potential donors to consider their decisions thoroughly, as inferred from the participants' opinions. Gözde states: "I never thought about myself because it happened so fast. I was surprised at my behavior at that moment. I tried to cheer up my mother and the people around me as if I was not going to go into surgery. I mean, I was telling and showing other good examples. I was not even scared at that stage. Because there must have been no opportunity." Even with the knowledge of the situation's urgency, it is difficult to understand why everything happened overnight. Leyla, 19 years old, gave her liver to her mother, who was in a coma. She states, "The psychological test I took was not very detailed. I think because of the urgency of the situation. A psychiatrist came to the room where I was lying and asked me how I was feeling. I said I was scared and worried. I remember it very clearly. He said it was normal for me to be scared and say such suggestive things. He signed and left anyway. It didn't even take five minutes." Although she expressed feelings of fear, the response was that this anxiety was normal. It gave the impression that it had not been addressed but rather was not taken seriously.

A further consequence of the interviews was that the women who asserted their ability to withdraw from donation at the last minute also reported the use of tranquillizers the previous night. Although the use of tranquillizers before surgery is a routine medical practice for donors, it is important to note that this may potentially impact their ability to express their concerns and withdraw from the donation. Our knowledge of why this was done is limited.

The study highlights significant deficiencies in the information provided to organ donors regarding the complexities and potential long-term impacts of organ transplantation procedures. Many critical questions remain unanswered, ranging from surgical details to post-operative health outcomes, raising concerns about the validity of consent without comprehensive knowledge. The uncertain long-term health effects on donors, such as the possible association with dementia, pregnancy, menopause and other conditions, underscore the need for rigorous and ongoing follow-up studies. Addressing these gaps is essential to ensuring ethical practices that protect donors' autonomy and well-being in organ transplantation.

## VII. Altruism

Women have expressed a shared view that sacrifice is a gendered emotion, particularly emphasizing that autonomy has not been used in the sense of being completely free from everything. The most obvious reason for altruism in organ donation stems from women's repetition of socially con-

structed gender roles such as motherhood, self-sacrifice, and benevolent daughter. It can be explained by traditional male-female roles in which women feel obliged to take care of their sick family members. Mine states, “I think women give more organs in the world. I have a lot of friends I know. I have 3-4 friends who are liver donors. All of them are women. I don’t know; I think it may be the character. They feel more sad if they lose their loved ones. I think men are less sad. Women are more sacrificing.”

It is considered “normal” for women to donate an organ from their own body, and it is often a part of their caregiving and fertility roles. It is associated with the expectation of social sacrifice. The devotion and sacrifice expected from women cause them to regard this action as “normal.” As Zeiler notes, this is also a normalization of bodily exchanges in medicine.<sup>41</sup> Nevertheless, when considering altruism, it can be argued that the donation of an organ from one’s own body to another individual represents the pinnacle of selfless acts. I do not intend to suggest that the action in question was undertaken solely for benevolence. Women have placed themselves at risk for those they love or do not love and have undergone this operation. This decision is a voluntary and altruistic action resulting from calculations and reckonings made by women in their inner worlds. But this altruistic behavior can be seen as a bargain to free them from all contracted responsibilities. In the absence of greater environmental pressures and obligations, it is possible that the decision would have been reached differently.

Women were aware of their oppression and marginalization. Figen states: “It may be because women have a softer temperament. Alternatively, they can give up things more easily. Give an example from the crisis. Women are so accustomed to being the first to go out of favour that men cannot easily give up their jobs. Therefore, women may be approaching things conscientiously because they know this. Is this a good thing? It depends on the place. If she is going to be a mother, yes, she should be. However, if it is a professional job, no. If you make a conscientious decision in that environment, you are not taken seriously, your opinions are questioned.” Living organ donation is considered an extension of social expectations, and the act of donation, in parallel with the motif of sacrificial motherhood, is highly selfless, and self-sacrificing is defined as a form of behavior. Therefore, this situation is considered a woman’s innately altruistic behavior, naturalized and normalized by their tendency to be.

<sup>41</sup> Kristin Zeiler, “A Phenomenological Approach to the Ethics of Transplantation Medicine: Sociality and Sharing When Living-With and Dying-With Others,” *Theoretical Medicine and Bioethics* 35 (2014): 369-388.

### VIII. Conclusion

The analysis identified key factors shaping *autonomy*, which in the context of living organ donation refers to the individual's right to make decisions about their own body and health, including family relationships, paternalism, criticism of disclosure and informed consent, and altruism. Family relationships emerged as pivotal, with constructed expectations within family dynamics significantly influencing donors' decisions. Donation was expressed as a concept that must be endured due to necessity, not a process decided by free will. In the context of live organ donation, women perceive the moral dilemma of saving someone versus allowing oneself to die as a matter of care and responsibility rather than solely as a right to not harm oneself. Being a live organ donor also goes beyond the legitimized discourse of altruism; it involves expectations, bargaining, and negotiations. By making sacrifices, women expect recognition and respect.

Societal norms, particularly those related to motherhood, create a sense of obligation and support. Mothers, sisters, and wives often feel compelled to donate due to the societal expectation of selflessness. These expectations shape donors' sense of duty and acceptance within their families, highlighting the complex interplay between personal choice and societal pressure.

Paternalistic attitudes in healthcare settings often stifle donors' decision-making agencies. Medical professionals, assuming a directive role, often overshadow the donors' autonomy, leading to a power imbalance in decision-making. This dynamic underscores the pressing need for a more balanced and respectful approach that genuinely considers the donor's perspective and autonomy. The urgency of this shift towards more patient-centric care is evident, as it can significantly improve the donor's experience and decision-making process.

Criticism of disclosure emerged as another significant factor. Donors often find themselves at a disadvantage in understanding the full implications of their decisions, needing help to navigate complex medical information. This criticism underscores the crucial role of effective communication between donors and medical practitioners. Both parties need a comprehensive understanding of each other's perspectives to bridge this gap, which can lead to increased uncertainty and stress for the donors, further complicating their decision-making process.

Altruism, intertwined with personal sacrifice, moral duty, and the normalization of the donation process, played a crucial role. This sense of altruism is driven by cultural norms and expectations of caregiving

and nurturing, often overshadowing individual autonomy. The pressure to conform to these norms can lead donors to prioritize the needs of others over their well-being, reflecting broader societal values that valorize self-sacrifice, particularly among women.

This study comprehensively examines the gendered dimensions of autonomy in living organ donation in Turkey. Integrating feminist theory and the concept of autonomy highlights the nuanced experiences of women donors and underscores the need for a deeper understanding of how gender inequalities shape medical practices. The findings reveal significant gender disparities in donor availability, access to services, and post-transplant care responsibilities, all influenced by cultural norms and gender dynamics. These disparities are often perpetuated by 'medical biases,' which refer to the systematic favouritism or discrimination towards certain groups in medical practices, in this case, women donors.

Furthermore, this study contributes to feminist autonomy theories by providing empirical insights into women's lived experiences and interpretations of autonomy in the context of living organ transplantation. These insights include specific instances where women donors felt their autonomy was compromised or respected and how they navigated the societal and familial pressures. By including women's voices and experiences, this research challenges the tendencies that objectify the body and offers a critical perspective on the intersection of medical practices and societal norms. The insights gained from this study underscore the importance of considering gender and autonomy in discussions of organ transplantation, advocating for more equitable and inclusive approaches in healthcare.

This study offers a significant contribution to the understanding of gendered autonomy in living organ donation. It reveals the intricate ways in which societal norms, familial expectations, and medical practices intersect to shape women's experiences and decisions. By highlighting these dynamics, the study calls for a reevaluation of consent procedures and a move towards more inclusive, respectful, and gender-sensitive practices in organ transplantation. The findings emphasize the necessity of addressing gender biases and ensuring that women's autonomy is respected and supported in medical contexts.

I would like to express our deepest gratitude to the women donors who shared their meaningful stories, forming the most valuable parts of the fieldwork. Their life stories have significantly contributed to this project, adding true meaning and depth to this research. Each of them has made an important step for humanity, positively impacting the lives

of others. By being at the heart of this research, they have greatly contributed to raising awareness about organ transplantation. Their participation has not only enriched this study but also contributed to the broader awareness of organ donation. I hope this work will shed light on the lives of future donors and those awaiting transplants. I extend my sincerest thanks to them and salute the women who shared this unique experience.

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