

Does Autonomy Really Exist for Impoverished Kidney Vendors?

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The following paper will explore autonomy in the context of impoverished kidney vendors. I argue that people who live in impoverished countries lack the ability to provide true and informed consent to sell their organs. The focus will be on kidney vendors in Pakistan. I am writing from a social work lens and consider the oppression, exploitation, and injustices that these vendors have faced. Relational autonomy acknowledges that our relationships and environment influence our ability to be autonomous. Therefore, the impoverished vendors' autonomy in Pakistan is threatened in the context of selling their organs. Lastly, this paper will acknowledge the counterargument that selling one's kidney should be an option for anyone, regardless of socioeconomic status, and acknowledge the value that a sold organ can bring both the vendor and the recipient.

INTRODUCTION

Selling one's organs is a hotly debated topic across the world. There are legitimate arguments in favor of both sides. The following will argue that people who live in impoverished countries lack the ability to provide true and informed consent to sell their organs. The focus will be on kidney vendors (people who sell their organs) in Pakistan. Although they may appear to be autonomous adults, they lack a range of good options to make money and, therefore, they cannot provide true informed consent. Poverty in this context is coercive and it inhibits the voluntariness that is needed for consent. A social work lens would encourage one to consider the oppression, exploitation, and injustices that these vendors have faced. "Relational autonomy," a term coined by feminist ethicists, acknowledges that our relationships and environment influence our ability to be autonomous. Therefore, in the context of selling their organs, the impoverished vendors' autonomy in Pakistan is threatened. Lastly, this paper will acknowledge the counterargument that selling one's kidney should be an option for anyone, regardless of socioeconomic status and acknowledge the value that the sold organ can bring both the vendor and the recipient.

Transplant tourism is when patients from Western countries travel to the eastern hemisphere to purchase a lifesaving organ. This has become increasingly common. Commercialized body parts have been sought after by Westerners, likely due to the very long wait times for deceased donor organs in their home countries. Legislation and edicts from a range of transplant societies have failed to prevent this from happening. Several reports have shown that there is a "kidney bazaar" thriving in India and Pakistan (Sajjad, Baines, Patel, Salifu, & Jindal, 2008). In the United States, roughly 3000 people die each year waiting for a deceased donor kidney transplant (Aubert, Reese, & Audry,

2019). Despite these deaths, selling an organ in the U.S. is illegal, and one can be fined up to fifty-thousand dollars (\$50,000) and or five years in prison for breaking this law (National Organ Transplantation Act (NOTA) of 1984, Prohibition of Organ Purchases). The United States has a rigorous psychosocial screening process for prospective live donors; part of these assessments is trying to ensure that people are donating voluntarily. American transplantation associations have repeatedly spoken out and taken a strong stance against paying donors, saying that it is illegal and unethical (Friedman & Friedman, 2006). Therefore, donors in Pakistan, for example, are more vulnerable to being exploited than American donors because regulations are stricter in the U.S.

The Ethical Context

The Ethics Committee of the Transplantation Society put forward a policy statement prohibiting transplant teams from being involved directly or indirectly with the buying or selling of organs (Friedman & Friedman, 2006). Within five years, the World Health Organization (WHO) issued a similar ban. They produced a document titled "Guiding Principles on Human Cell, Tissue, and Organ Transplantation" (2010). In the preamble, the document states it was provoked to create procedures, due to the shortage of organs and subsequent human trafficking of organs from unrelated donors. Guiding Principle 3 states the following: "Live donors should be informed of the probable risks, benefits, and consequences of donation in a complete and understandable fashion; they should be legally competent and capable of weighing the information; and they should be acting willingly, free of any undue influence or coercion." (p. 3). This principle does not mention the socioeconomic factors that may influence autonomy. There is an individualistic emphasis on how one achieves autonomy. The reality is, many of these vendors in Pakistan are not free of undue influence and coercion, even if it is subtle.

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This principle does not explore the complexity of attaining autonomy. The modern phase of bioethics in the 1960s and 1970s had an overly simplistic view of autonomy. The assumption was that both the physician and the patient were rational decision-makers with equal power. However, there were unspoken assumptions that both the physician and the patient were male, white, English-speaking, and able-bodied (Brody, 2009). A social work lens would encourage bioethicists to try and understand autonomy more deeply. The term “relational autonomy” is defined as the explicit recognition that autonomy is pursued in a social context and that one’s social context can influence one’s opportunities to develop and express autonomous skills. It is therefore imperative to understand a person’s social location to see if they can adequately express autonomy. Autonomy is influenced by both social forces and oppression; hence we need to evaluate society and not just the individual when trying to determine if someone can act autonomously (McLeod & Sherwin, 2000). This understanding of autonomy is crucial when trying to determine if kidney vendors in Pakistan have the necessary skills to make autonomous decisions.

Kidney Transplantation in Pakistan

Kidney transplantation began in Pakistan in the late 1980s with no national law to regulate the process. Kidney tourism is well known in Pakistan and has remained limited to private hospitals. A study that was conducted in Pakistan interviewed 32 vendors, who sold their kidneys, and the data is startling. The term “vendor” has been carefully selected because these people did not donate their kidney. All of the vendors, except two, sold a kidney to pay off their debt. These vendors represented the most socioeconomically disadvantaged people in Pakistan. A majority were still in debt or had new debts after the surgery. None of the vendors were paid what they were originally promised. All of them used a middleman, whom they had to pay. None of the vendors, except one, would recommend selling their kidney, including those who paid off their debt (Moazam, Zaman, & Jafarey, 2009). Another study that was conducted in Pakistan concluded that 90% of the vendors were illiterate, 69% were laborers who acted like slaves to landlords, 12% were housewives, and 8.5% were unemployed. The majority vendored for debt, and 88% had no financial improvement after donating. Lastly, 98% reported that their general health deteriorated after selling (Naqvi, Ali, Mazhar, Zafar, & Rizvi, 2007).

Vendors in Moazam and colleagues’ study complained of various issues, including pain related to the surgical incision, even those with a nephrectomy from over three years ago. Many complained of tiredness, weakness, and all of them said they could not work as hard they could as before the nephrectomy. Some of them also complained about a sense of emptiness. Fifty percent of the vendors said that they felt anxious and felt a sense of hopelessness about their life. Even

those who paid off their debt, felt a deep sadness and regret about the act. There was also a sense of being victimized and feeling cheated by the medical profession. None of the vendors knew the name of the surgeons or other doctors involved in their care, but they all knew the name of their middleman. Hospital staff were described by the vendors as being in a business of theft. The vendors studied were specific to Pakistan, but the researchers felt their circumstances, such as their economic and social inequalities, were a reality for many other vendors, regardless of the country in which they live (Moazam et al., 2009).

A Case Example in Pakistan

Moazam et al. (2009) brought names and faces to the stories of kidney vendors in Pakistan. They wrote about a case study, Boota and Nazeeran and their family, whom they felt resembled many of the narratives that they heard while conducting their study. This narrative is crucial in shedding light on the autonomy, or lack of autonomy, for these vendors. Boota and his wife, Nazeeran, lived in a room with their six sons and two unmarried daughters. The consent process for Boota, Nazeeran, and their son to sell their kidneys consisted of going to a small court, being asked if they were giving their kidneys happily, and then putting a thumb print on a piece of paper as a signature. They were not aware of what was written on the papers, nor could they keep the papers. Boota’s son reported that Boota wakes up in the middle of the night screaming that someone is going to take him away, and Boota thinks he is better off dead. Their son said that both of his parents have insomnia and wake up crying at night. It is clear from this story, that both Boota, Nazeeran, and their son were all extremely vulnerable due to being in a dire financial situation and donated out of financial pressure.

The Counterargument

Although many agree that selling one’s kidney is due to financial pressure, and the practice should be illegal and abolished, others would argue that this practice is both necessary and ethical. Vendors are, in fact, participating in a risky behavior. However, many of us do: Sky diving, volunteering for the military, working on oil rigs, smoking cigarettes, and drinking alcohol, for example, are all risky behaviors in which many Westerners partake. An argument presented is that lacking wealth should not prevent you from making a rational decision. By prohibiting the selling of organs, we still leave people just as poor and disadvantaged. Eliminating this type of transaction takes away one option for people trying to improve their financial situation. A suggestion for protecting vendors is to legalize and regulate kidney sales through an international market. This could result in better protections and guaranteed money for vendors. Money saved from the costs of dialysis could lead to more money for kidney vendors (Friedman & Friedman, 2006). A market that is ethically supportable with safeguards against exploitation could be better achieved with a single-

purchaser system. The reality is that people are dying every day while waiting for an organ. In 2010, 2.62 million people received dialysis worldwide and the need for dialysis was projected to double by 2030 (Luyckx, Tonelli, & Stanifer; World Health Organization (WHO), 2018). There are clearly compelling arguments in favor of selling one's organs.

Moazam et al. (2009) are not convinced by the counterarguments in this debate. They feel the poverty and restrictions they witnessed in Pakistan make it difficult for those people to imagine an alternative to selling one's kidney. Arguments in favor of traditional autonomy, and the notion that people should have the ability to take on risks, cannot be compared to sky diving or joining the military in the context of impoverished kidney vendors. Moazam et al. (2009) feel people are out of touch with reality if they argue that impoverished people should be able to control their own bodies. This is far too narrow and naive in their opinion. In response to a legalized market, they assert that we cannot overlook that poor and disadvantaged people will still be selling their kidneys whether the market is legal or not. They question if a legal market would really allow people to exercise a right or a freedom. They argue that even with a legalized market we fail to really see social inequalities and recognize the lived experience of society's most vulnerable.

A Clinical Social Worker Perspective

As a social worker in a large urban teaching hospital, I have the privilege of providing post-transplant care on the acute care floor. The issue of purchasing a kidney abroad from a vulnerable person leaves me very torn. I see the other side—the recipient. One case will always stand out to me. I was asked to see a young man who openly admitted to me that he purchased a kidney in Sri Lanka. He even told me exactly how much he paid, and how hard he worked to pay for it. In front of me I saw a vulnerable man, desperate, and depressed. His new kidney was infected, and he would do anything to avoid a life on dialysis. He had already experienced two years on dialysis before he purchased his kidney, and he told me, quite frankly, that it is not a life worth living, according to his own personal perspective. He even admitted that if his body rejected this new kidney, he would rather pass away from kidney disease than live on dialysis. This patient represents the other side of this controversial topic. As a social worker, I am trained to think about the larger picture. How can I only think about this vulnerable young man and not consider the vulnerable vendor? I do not have an easy answer to this worldwide crisis. I do, however, recognize and appreciate the struggle of the recipients and the sheer desperation they feel when they go abroad to purchase a kidney. As a clinician, I am left very conflicted. Although conflicted, I know for certain that it is my ethical and clinical duty to support, advocate for, and respect the patients who sit in front of me and share their stories, desperation, and hardships with kidney disease, while using a non-judgmental approach.

CONCLUSION

In sum, there is no clear or straightforward solution to the organ crisis that the entire world is currently experiencing. Even with a legalized market for organ selling, there still remains the issue of exploiting society's most vulnerable people. Poverty, especially in the context of selling an organ, can be coercive because it significantly affects one's ability to provide informed consent. The reality is that autonomy is socially situated. Therefore, kidney vendors in Pakistan, who are some of the most socioeconomically disadvantaged members of society, have provoked one to question if there was any degree of choice in "voluntarily" selling their kidneys. There are clear forces of oppression that we cannot overlook. Oppression may implicitly or explicitly limit the options that are available to an oppressed group. There is an intersection between oppression and self-trust or distrust (McLeod & Sherwin, 2000). Vendors in Pakistan may not have been capable of self-trust, and therefore not able to make a fully autonomous decision in the context of selling their kidneys.

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