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Gender Bias and Organ Transplantation in Nepal

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Women in Nepal are less likely to receive proper, high quality medical care than their male relatives. Live donor kidney transplantation provides a compelling example of such disparities, as 84 percent of recipients are male, 75 percent of donors are female, and most kidneys are transferred from mother to son and from wife to husband. In the case of transplantation, women are not just denied healthcare, they are also responsible for the health of their male kin. Based on semi-structured ethnographic interviews with transplant patients, organ donors, dialysis patients and relatives, this article elaborates on the social and economic factors that have created an extreme gender bias in transplantation.

We argue that women, whose livelihoods largely depend on their husbands, donate kidneys out of self-protection and a sense

of duty. Conversely, men receive kidneys but rarely donate them to women, because the health of men is considered a more productive economic investment than the health of women. We reject the notion that wives are directly coerced or pressured into donating kidneys to their husbands. Rather, we argue that female kidney donors make thoughtful decisions that serve their best interests, and allow them to assert some control over their lives. It is, however, Nepal's patriarchal society that both necessitates and limits such assertions of power.

Keywords: transplantation, gender, kidney disease, living donor transplantation, healthcare access, Nepal.

Introduction

On a bright Tuesday morning, the first day of the Nepali New Year, a small crowd gathers in Kathmandu's Dashrath Rangashala Stadium. Men and women stretch, preparing to compete in track events and a football match. It's an unlikely group—surgeons, nurses, transplant patients and kidney donors alike are gathered for Nepal's sixth Annual Transplant Games. Patients and donors race around the track, proving that transplant recipients and donors can fully recover to achieve physical and athletic greatness. Winners are congratulated, medals are passed out, and the football match ends in a friendly draw. It's a festive morning, one in which patients celebrate their recoveries and doctors celebrate their progress in bringing high quality transplants to Nepal. Yet the transplant games also highlight a major issue that threatens healthcare access in Nepal: a gender bias in access to treatment. While a large field of male transplant recipients compete, only a handful of female recipients participate. This reflects the reality of transplantation in Nepal, where the 84 percent of kidney recipients are male, and 75 percent of donors are female.

This article elaborates on transplantation as an example of gender disparities in healthcare in Nepal. We demonstrate how certain social and economic factors have created an extreme gender bias in organ donation. Focusing on respective gender roles and expectations, we argue that the most compelling motivation for a woman to become organ donor is self-protection. Men, who occupy a far less vulnerable position in Nepali society, lack such a persuasive motivation to donate. This factor, in addition to a woman's obligation to protect her children, severely limits the donor options available to women. Ultimately, we argue that legal donor restrictions exacerbate the gender bias and place an unequal burden on women—especially wives and mothers—to donate kidneys.

Kidney Transplantation in Nepal

The athletes competing in the Transplant Games are coping with a chronic disease and have recovered from a major surgery. They have also overcome major social and economic obstacles to receive a treatment that is out of reach to most other Nepalis. According to the Human Organ Transplant Center (HOTC) in Bhaktapur, each year an estimated 3,000 people develop end stage renal disease (ESRD) in Nepal.¹ Due to the realities of health care access in Nepal, most cases of ESRD go undiagnosed and untreated. HOTC estimates that only ten percent of ESRD patients receive proper treatment, and the rest die within months; such estimates are consistent with observations in Pakistan and India (Sakhuja and Sud 2003).

Nepalis who do access the necessary care have two options: either receive lifelong dialysis at one of many hemodialysis centers in Nepal, or pursue kidney transplantation. Without one of these therapies, ESRD is fatal. But neither option is ideal for patients who, at this stage in their pursuit of healthcare, have likely incurred massive debts. Dialysis is time consuming and a life-long burden, and hospitals report a high dropout rate (Khakurel, Agrawal, and Hada 2009). Transplantation requires significantly higher costs up-front, but in the long run allows patients to live full and productive lives—working, earning money, and raising families.

Kidney transplants became available in Nepal in 2008 (Chalise 2010). Prior to that milestone, Nepalis sought transplantation abroad—usually in India—where costs were significantly higher and where the majority of Nepali patients purchased kidneys illegally from unrelated donors (Dulal and Karki 2008). Since 2008 however, Nepalis have been able to receive transplantation in their home country. Currently three hospitals (HOTC, Teaching Hospital and Bir Hospital) perform kidney transplantation, but HOTC, a government hospital, is Nepal's only facility dedicated solely to transplant. Currently only kidney transplants are available, though surgeons hope to soon introduce liver transplantation.

Despite significant progress in availability, there are still limitations to transplantation in Nepal. One such factor is cost. At HOTC transplantation costs about three lakh Nepali rupees (\$3,000 USD), two lakh (\$2,000 USD) of which is reimbursed by the Nepali government. Patients must also take medication for the rest of their lives, the cost of which is estimated to be about 15,000 NRs (\$150 USD) per month. For this medication the government offers one lakh (\$1,000 USD), which covers just over six months of medications. Despite government reimbursements, the upfront cost of three lakh Rs. is prohibitively high for most Nepalis.

In Nepali and international media, kidney transplantation in Nepal is most often associated with trafficking. Indeed, a global black market for human organs exists and its presence is deeply felt in many parts of Nepal. Stories abound of impoverished villagers being coerced, duped or tricked into 'donating' a kidney in exchange for money or land (Wade 2014; Pokharel 2014; Haviland 2004). Often these victims are not given the compensation they were promised and are left in a worse economic condition, and with poorer health, than before the operation (The Asia Foundation 2015).

Despite the immediacy of the organ trade in Nepal (and its significance in medical anthropology), it is not the focus of this article. It is, however, relevant in its effect on transplant policy in the country. In an attempt to curb organ trafficking, transplantation legislation stipulates that donation must occur only within families (Government of Nepal 1998). That is, a transplant patient may receive a kidney from their parents, siblings, grandparents, children, aunts, uncles, nephews, nieces, and grandchildren or spouses, parents-in-law, step-parents, and adopted children with whom the legal relationship has existed consistently for at least two years (Government of Nepal 1998). While this may seem like a long list, in practice it is quite limiting. Close friends, neighbors, other relatives (such as cousins) and fictive kin are all restricted from giving. Furthermore, deceased donor organ procurement is not currently available in Nepal; only live donations are possible.

These policies limit donors to a very small pool. They also necessitate that the decisions surrounding organ transplantation are made within families, and are deeply influenced by each family's unique tensions, priorities, and biases. A limited donor pool heightens the importance of the social dynamics and cultural environment that, in part, dictate the ways in which families function.

Throughout our interviews, many participants expressed deep concerns for the wellbeing of live kidney donors; some even equated donation with death, which is an extremely rare occurrence (Segev et al. 2010). It is important to note that globally, the vast majority of live kidney donors go on to live normal, healthy and productive lives, and that live kidney donation is the predominant form of kidney transplantation worldwide (Muzaale, Massie, Wang, and et al. 2014; Gross et al. 2013; Delmonico and Dew 2007). However, this perception, that donation confers weakness and a high risk of mortality, informs the decisions of many of our participants.

Gender Bias and Healthcare Access

Inequalities in access to healthcare on the basis of gender are well documented in Nepal and other countries in South Asia (Pandey et al. 2002; Gupta 1987; Chen 1981; Leone, Matthews, and Dalla Zuanna 2003; Karki 1988; Pokhrel et al. 2005). Studies show that families are more likely to pursue treatment for sons than daughters, and that healthcare for sons is likely to be more expensive and of higher quality than healthcare for daughters (Pandey et al. 2002; Gupta 1987; Pokhrel et al. 2005). Both caste-based and economic arguments have been made to explain such biases. The narrative of 'son preference' dominates

discussions of gender biases, and in Nepal, son preference is shown to influence decisions regarding fertility and contraception (Leone, Matthews, and Dalla Zuanna 2003; Karki 1988). Karki claims that such biases come about due to cultural practices, specifically the responsibility of sons to carry out death and post-death rituals for parents (Karki 1988). A study from Punjab, India, suggests that the flow of resources from a daughter's natal home to her husband's home is responsible for "strong and mutually reinforcing incentives for parents to successfully rear sons rather than daughters" (Gupta 1987: 96). According to these claims, women are more a burden to a family than an asset, and men's importance in a family is primarily ritual. The findings in this paper, however, are less consistent with such narratives and are more aligned with assertions made based on research in Bangladesh that disparities arise because of decisions regarding financial investments (Chen 1981). Daughters, the researchers claim, have relatively limited opportunities to work and contribute financially to families, whereas the health of sons is a promising economic investment (Chen 1981).

It is crucial to note that gender relations in Nepal are highly influenced by caste and ethnicity. A woman's role in her family and community varies based on her caste, and as Mary Cameron writes, "In everyday life, the worlds of low- and high-caste women are vastly different, physically separated as they are by the rules of caste interaction and the different ways caste shapes their lives," (Cameron 1998: 46). For this reason, it is impossible to make claims about gender bias in transplantation that apply to Nepali women as a whole. And in a study with a small sample size such as this, it is imprudent to draw conclusions about associations between certain behaviors and caste. However, when discussing factors that may be influenced by caste we will try to consider how caste and ethnicity status may influence the decisions of our informants.

Gender Bias and Organ Transplantation

While a gender bias in organ donation is not unique to Nepal or even South Asia, it is certainly observed to a unique extreme in the region (Bal and Saikia 2007; Malattiri 2014; Muthusethupathi 1998; Bhowmik et al. 2003; Chandra 2001). The gender bias being addressed here is the disproportionate number of females who are donating and males who are receiving kidneys. Slight biases of this nature have been observed elsewhere, such as in Europe, the US, Canada, Japan, and China (Salter et al. 2014; Kayler et al. 2003; Achille et al. 2007; Takagi 2015; Liu et al. 2013; Øien CM 2005; Hogan et al. 2016). In the US for example, women are 1.45 times less likely to have discussed transplantation

with care providers (Salter et al. 2014), and make up 68 percent of spousal live kidney donors (Kayler et al. 2003).

Yet nowhere is the bias as extreme as in South Asian countries such as Nepal and India. In India, studies across the country showed a high reliance on female donors, especially wives and mothers (Bal and Saikia 2007; Malattiri 2014; Muthusethupathi 1998; Bhowmik et al. 2003; Chandra 2001). In various hospitals, the percentage of female donations ranged from 66 percent to 74.2 percent (Malattiri 2014; Muthusethupathi 1998; Bal and Saikia 2007). Analyses of spousal donations reveal the high rates of wife to husband transfers; the percentage of female spousal donors ranged from 87.7 percent to 94.5 percent (Bal and Saikia 2007; Malattiri 2014; Bhowmik et al. 2003). Likewise, males make up the majority of recipients, ranging from 76.2 percent to 88.9 percent in three studies (Malattiri 2014; Muthusethupathi 1998; Bal and Saikia 2007).

The gender imbalance in Nepal mirrors that of their Indian neighbors. Between the introduction of transplantation in the country in 2008 and April 2015 when fieldwork for this study was completed, two of Nepal's three transplant facilities have completed a total of 178 transplants. 84 percent of these recipients were male, while 75 percent of donors were female. 65 percent of kidneys were transferred from female to male, while only six percent were transferred from male to female. Mother to son transfers were the most common, making up 30 percent of all transplants. In the spousal category, 87 percent of donors were wives giving to their husbands.

This extreme gender bias is recognized in Nepali academic literature, and is increasingly a topic of discussion in the popular media as well. A paper reflecting on Nepal's first year of transplantations states that "females dominated over males in donation ... this might be a reflection of a male dominated society" (Chalise 2010). Many newspaper articles have also highlighted this bias, and transplant centers' efforts to provide more equitable care (Ojha 2014a, b; Dahal 2014).

Kidney transplantation in Nepal is clearly gendered in two directions; at the receiving end of the exchange women are underrepresented, while at the donating end they are overrepresented. The issue, then, must be addressed from both directions; why women are giving overwhelmingly to men, and why so few women receive kidneys.

Methods

This paper is based on ten months of ethnographic fieldwork at the Human Organ Transplant Center (HOTC) in

Bhaktapur and in partnership with the Aarogya Foundation in Lalitpur. Using a convenience sample, we recruited participants in person during post-transplant follow-up visits, hospitalization for transplant, and dialysis sessions. We interviewed transplant recipients, donors and family members, as well as women on dialysis who could not find a donor. In total, we conducted interviews with at least one member of forty-nine families, resulting in a total of sixty-seven interviews, twenty-nine of which were with transplant recipients, thirteen with donors, six with family members and nineteen with women on dialysis. Transplant patients, donors and relatives were recruited following regular check-ups or during their post-operative recovery at HOTC. Women on dialysis were recruited during their regular trips to HOTC for dialysis.

Because patients come from all over Nepal, it was not feasible to seek out participants in their home villages. Thus, we were only able to interview participants who came to HOTC of their own volition during the research period, posing a limitation and possible bias to our sampling. Despite this, 83.3 percent of transplant patients included in this study were from outside the Kathmandu Valley (Table 1). The median annual household income reported by our participants was \$2,492 USD, relatively high compared to the national median of \$1,175 USD (Central Bureau of Statistics 2011). We suspect that the incomes reported by our participants are biased due to social desirability bias, but our data do suggest that those who receive transplants at HOTC were wealthier than the general population. Our intentions to begin interviewing men on dialysis were dropped following the major earthquakes that occurred during the study period, adding an additional bias to our sample. Most interviews were conducted in Nepali; only four were conducted in English. A language instructor provided further translation and transcription assistance. Ethical approval for this study was provided by the Nepal Health Research Council and the research was funded by Fulbright—USEF Nepal.

Women as Donors

Familial roles govern who is responsible for the livelihood and wellbeing of each family member. One who is responsible for the life of another is compelled to give a kidney to that person should they need it, but the exchange would rarely occur the other way around.

	Donors N=13	Recipients N=29	Relatives N=6	Women on dialysis N=19
Age (median)	42	33		48
Female (%)	46	21	67	100
Caste (%)				
Bahun	23	10	0	
Chhetri	38	34	50	
Janjati	38	38	17	
Madeshi	0	3	17	
Dalit	0	14	17	
Median Annual Household Income USD: \$2,492				
From Outside Kathmandu Valley: 83.3%				

Table 1. Participant Characteristics.

Mothers to Sons

The clearest example of this is the relationship between parents and children. Parents are, indisputably, responsible for the lives of their children, and are usually the first to offer to donate a kidney. Parents are motivated to donate in part by love or affection (Nep. *maya*) towards their children. When asked why parents offered to give, common responses were “out of love for my daughter” or “to save their son’s life.”

For many parents, the decision to give is straightforward and motivated by a sense of responsibility. One patient explained that “parents give quietly, without asking questions.” A mother who gave to her son explained “From the beginning, I said I would give. I got him married, I raised him, and now I will give him life. I myself will give.” When faced with a son or daughter suffering from ESRD, a parent’s compulsion to care for their child, even if the child is grown and with families of their own, extends beyond the typical parental duties of raising, feeding, and educating a child. For this mother, the chance to donate a kidney is an opportunity to save her son’s life and to demonstrate her devotion to him.

In this study, mothers were motivated to make sacrifices for their children, especially when fearing that their children would die before them. Two of the three mother donors we interviewed expressed this sentiment. One mother explained:

I decided myself that I would give [my kidney], and if I die it would be peaceful and nothing would happen. [My family] might cry for one or two days, but over time they would forget me. I have brought

up these children myself, and I myself will give life to my son.

The mother did not literally give up her life for her son; the vast majority of kidney donors go on to live normal, healthy and productive lives (Muzaale, Massie, Wang, Montgomery, et al. 2014; Gross et al. 2013). But in her mind it was a sacrifice: she gave up a literal piece of herself for her son, for whom she would give up her own life.

Despite this desire to give, parents are more likely than other, younger relatives to have health problems of their own that preclude their ability to give. Among our participants, morbidity such as heart disease, diabetes or obesity limited fathers’ ability to give. Indeed, a 2013 survey of risk factors for non-communicable disease in Nepal showed that men aged 15-69 are more likely than women to have three or more risk factors for diseases that disqualify one from organ donation (Aryal 2014). While mothers were more likely to bring up sacrifice and duty, fathers were also very willing to give. In many cases, fathers were the first to offer, but for health reasons they were more likely to be rejected. In our study, 38 percent of participants with mother-to-child transfers said the father initially offered to donate but was rejected for health reasons. This disproportionately left mothers responsible for donation.

There is also a significant difference between parents giving kidneys to sons versus daughters. Sons are viewed as a more promising economic investment than daughters, and daughters are more likely to be diagnosed with ESRD later in life, when parents are too old or diseased to donate. For these reasons, which will be discussed in length below, sons are more likely than daughters to receive a kidney from a parent.

Wives to Husbands

Researchers in India have suggested that many wives are coerced into donating to their husbands, and that when donating they are not acting of their own accord (Bhowmik et al. 2003). At least one Indian hospital only accepts wives as donors if no other relative is able to give (Bhowmik et al. 2003). Indeed, in many of the families interviewed for our study, wives were assumed to be the primary donor (or secondary, after parents).

In our interviews, however, we found very little evidence to suggest that women are being directly coerced into donating. As one patient, whom we interviewed in English, said about his wife, “She is ready. To give and to donate, each and every time, she is ready.” Wives themselves emphasized their willingness to donate and insisted that they decided to do so freely and of their own will; 100 percent of our participants who underwent wife-to-husband transfers said that the suggestion that the wife donate came from the wife herself. Wives generally cite one of two reasons when explaining their decision to donate.

The first reason is limiting the burden of illness and transplantation to herself and her husband. Two recipients used the same phrase to describe their wives’ decision to donate: *kina arulai dukha dine?* (Why give others the trouble?) One wife, who planned to give until the doctors discovered a prior health problem, expressed a similar sentiment. She knew about her health issue, but she tried to give anyway. She told us, “I said if we do the transplant it will be better. But I couldn’t ask his brothers. I am the closest one to him, so I should be the one to give. Without asking anyone, I said I would give.”

This line of reasoning—Why give others the trouble?—stems from the sense of social obligation wives often have towards their in-laws. Generally, a married Nepali woman carries a great deal of responsibility for the wellbeing of her husband’s family, and part of this is coping with and solving problems without burdening the rest of the family. When faced with a husband in need of a kidney, wives often feel that the most expedient option—the one that allows her to fulfill her duty to her husband and her in-laws—is to give herself.

The second reason wives so often donate to husbands is out of a sense of self-protection from widowhood. Without renal replacement therapy, renal failure is ultimately fatal, and women recognize that without a new kidney their husband will likely die. And for most women in Nepal, who are in highly interdependent relationships with their spouses,

this is not only a sad or heartbreaking prospect, but also a worrying one. Broadly speaking, single women in Nepal have limited social and economic opportunities, and the stigma for women whose husbands have died is even more extreme. This claim, however, is not universal. The role and status of women in Nepali families vary according to caste and ethnicity, and this is particularly true of the autonomy of women following the death of their husband. High caste Hindu widows are more often prohibited from re-marrying, and live lives that are both controlled by and entirely economically dependent on their male kin (Cameron 1998; Bennett 2002). Lower caste women, however, as well as some ethnic groups such as Newars and Tamangs have more opportunities to remarry (Cameron 1998; Pradhan 1981; March 1990).

Despite the diversity of caste among our informants (Table 1), participants of all castes cited widowhood as a motivation for donation. 66 percent of wife-to-husband pairs, and 50 percent of all families of married male recipients independently raised this point. One explanation came from a patient who explained his wife’s decision to give by saying “My wife? She said ‘if you die I will also die. But if you live we will live together.’” Speaking metaphorically, this wife equated her fears about widowhood with death. But by donating to her husband, she ensures both that her husband can live, and that she can live on as a valued and contributing member of society.

Another woman expressed her fears more explicitly: “What would life without a husband be? Life would be useless. I was in complete agreement to give. [If my husband died,] I would be so alone.” The same woman also discussed her parents’ fears when they learned about her husband’s disease: “They were worried and stressed. Very stressed. What will happen, how will things be, our one daughter, now there will be nothing, she has no children of her own, how will she live?” Being a young wife with no children, this woman finds herself in a very vulnerable position.

A woman married to a man with ESRD is in a very precarious situation. Untreated, her husband’s disease is fatal, but dialysis and transplantation will place an enormous strain on the family, especially her in-laws. The women we interviewed—as well as their husbands and families—were acutely aware of their uncertain futures were their husbands to die. As women describe it, the act of giving their husbands a kidney is less an act of selflessness and more an assertion of power and control over their own lives. In saving their husbands, women express that they are acting in their own self-interest.

However, the interests of wives are deeply intertwined with the interests of other family members, particularly their husbands. While decisions to donate can be viewed acts of empowerment, the power and control that women assert are limited by the interdependency of their relationship with their husband. Decisions to donate are not simply independently made; they are also acts of self-protection from the patriarchal society in which they hold a very vulnerable position. While the women we interviewed did not appear to be directly coerced or pressured into donating by their or their husbands' families, their decisions were certainly affected by the social and economic pressures imposed upon them. In this sense, wives are subject to a more structural form of coercion. Structural coercion may not occur at an individual level but rather at a social or political level (Fisher 2013; Schoen 2006). Furthermore, the threats that define coercion may not be of direct violence or harms, but rather of structural violence (Fisher 2013; Farmer 2004). Scheper-Hughes has also observed social and economic pressures to be a major factor in organ donation (Scheper-Hughes 2007). She notes, "Rather than celebrate the 'altruism' of women worldwide, we ought to be paying attention to the social pressures exerted on them to be living donors" (Scheper-Hughes 2007: 508). Among our participants, structural violence took the form of an uncertain future in widowhood, and despite the independent appearance of their decisions, these structures placed an undue burden on wives to donate to their husbands.

Women as Recipients

It is clear that men in Nepal are receiving more transplants than women. But to understand exactly what gender bias exists we must first ask if men experience higher rates of kidney disease. Could the apparent bias exist simply because more men are afflicted with ESRD? Unfortunately, there is insufficient epidemiological data on the prevalence of ESRD in Nepal to answer such questions. Despite this dearth of data on chronic disease, we argue that social and economic biases are limiting female patients' ability to seek transplantation. Our interviews with women on dialysis reveal that their (and their families') decisions regarding their health care are deeply gendered, and that these decisions generally serve to deny women care that is more often afforded to men. Like our interviews with transplant recipients, interviews with women on dialysis highlight a network of responsibility within families and ultimately revealed that very few people are responsible for the lives of adult, married women.

Parents to Daughters

Often the only donor options women have are their parents. As discussed above, parents are eager to donate kidneys to their sons, and the same holds true for daughters. Again, parents say they want to save their child's life because of love or affection. However, parents are more likely to be afflicted with their own diseases and ineligible to donate. 75 percent of the women on dialysis for whom having no donor is a barrier to transplant explained that their parents wanted to donate a kidney but were unable to for this reason. Women told of mothers with heart disease, fathers who had passed away or parents over the age of 60. One woman explained how important it is for parents to be able to give, and how difficult it is to find a donor other than one's parents:

You have to have the will (Nep. *man*) to give, you can't do it forcefully. You can't tell someone "Give yours! Give yours!" And whose soul (Nep. *man*) is that big? Where can you find a person like that? Mother and father are always ready but now that they can't what can we do? How can I do it?

Children to Mothers

Most of the women on dialysis that we interviewed are mothers with adult children. Sons and daughters alike offer to donate kidneys to their mothers, but mothers often refuse. In fact, 78 percent of those mothers for whom having no donor is a barrier to transplant expressed a reluctance to take a kidney from one of their children. Mothers are equally worried about taking a kidney from sons and daughters, but for very different reasons. Sons, mothers told us, are responsible for earning money and providing for their own families. Mothers fear that by taking a kidney from a son they will make him weak and unable to carry out his duties. One woman explained, "He's my only son. What to do? He has to take care of everyone. He has his own son to care for."

Another patient, a 54-year-old woman, told us her 20-year-old son offered to donate a kidney to her. Her son, who has four brothers and one sister, successfully passed his School Leaving Certificate and is now working in construction. But she rejected his offer. "I said, 'No I am already so old. You still need to work and feed your family.' I am already 54-years-old. How much longer would I live?" After having successfully raised her children, her parental duty makes her unwilling to put her son at risk to save her own life, even though he has volunteered.

Similarly, another female patient has two sons, both of whom are working, one of whom is employed at a bank. She explains that she is already sick and doesn't want to burden anyone else with her sickness or make anyone else suffer. This idea, that women should bear their own burdens, is consistent with an observation discussed above—that wives donate to their husbands because they don't want to “bother others.”

These mothers' reasoning also highlight the specific role young men play in their families. Sons, mothers told us, are responsible for earning money and providing for other non-earning family members such as wives, children, and elderly parents. Mothers recognize that to put a son at risk by asking him to donate a kidney is to risk his family's economic wellbeing. Likewise, mothers are reluctant to take from their daughters due to the familial roles young women occupy. Mothers explain that daughters, when married, must live in her husband's family's home and ultimately become a part of that family. Daughters are responsible for caring for these new families, and her wellbeing hinges, in large part, on her ability to maintain a good relationship with her in-laws. Mothers don't want to jeopardize their daughters' ability to do so by potentially 'weakening' them through this operation.

One patient explained, “My daughter said she would give, but I don't want to take from her. Even though she said she would give, why should I take hers? ... Then she'll go to someone else's house. What will happen in the future? Will her own husband support her?” Another mother of a 22-year-old, unmarried daughter and three sons told us, “If my daughter gave, what would we do? She would be weak and her brothers wouldn't take care of her. She has to work and feed herself.”

These mothers' concerns are consistent with the observations of researchers in India who found that no daughters donated, and explained this saying, “In India, married daughters staying with the husband's family are submissive to its dictates ... Hence parents do not expect a married daughter to donate (to their family), as they want to spare her hardship on this account in her relationship with her husband's family” (Malattiri 2014). Without the support of in-laws, mothers fear that daughters are unable to care for themselves. This fear and the subsequent rejection of daughters as donors demonstrate how mothers take precautions to protect daughters from social vulnerabilities, even as they make themselves more vulnerable. Furthermore, we see again here how mothers seem to value the lives of their children above their own. Mothers will sacrifice their own lives to ensure the longevity of their children.

Husbands to Wives

Women on dialysis consider their husbands as a 'last resort' option for organ donation. The responses of husbands to the needs of their wives on dialysis vary greatly. Some are clearly and explicitly uninterested in giving, telling their wives they won't donate a kidney to them. Some husbands are interested in giving, but for financial reasons the family can't pursue transplantation. Other husbands tell their wives they have health problems or simply the wrong blood type. Some of these claims are legitimate, such as one husband who is overweight. Yet some claims are more likely fabricated excuses than legitimate concerns. One woman we interviewed said that her husband told her he couldn't give because he was “weak,” but he couldn't explain why or articulate symptoms. Another woman acknowledged that her husband's mismatched blood type was a convenient excuse, saying that he wouldn't give anyway; “He'd get scared.”

Of note here is the contrast in responses of husbands and wives to their respective spouses' illnesses. While women worry about their own livelihood if their husband were to die, men do not seem to be motivated by this concern. Single men do not face the same stigmas and difficulties faced by single women; they are able to remarry, raise new families, and work. Thus the social and economic consequences of a deceased wife are far less of a concern. While husbands may want to give to their wives for a variety of other reasons, they are not motivated to do so out of self-protection. Indeed, until this research project concluded in May 2015, there had been no husband to wife transplantation at HOTC.

Organ Transplants and Economic Security: Considering Gender, Caste, and Class

Research shows that live kidney donors go on to live normal, healthy, and productive lives (Muzaale, Massie, Wang, Montgomery, et al. 2014; Gross et al. 2013). Yet that concept is difficult for families to truly believe. 54 percent of women on dialysis and 33 percent of all families interviewed revealed their main concern about men donating to be their ability to still earn money after surgery. Patients and their family members expressed worries that men won't be able to maintain their current jobs and thus “can't earn money like [they] did before.”

Neighbors and relatives echo their concerns, telling patients they shouldn't let men give up a kidney. One woman, the wife of a donor who gave to his brother, received negative feedback when she told friends and family about her husband's donation. They told her, “You and your family

have to work and eat, and your children are studying. It will be so hard for them to continue their studies² ... Your husband has to work and feed you, but he'll be so weak. Don't let him give!" Concerned family members dissuaded one husband who was willing to give to his wife, telling him they worried about his ability to earn. The patient's mother, who ultimately gave to her daughter, said "I told him not to give. [I said] 'you'll be weak after the operation. Your children are small. The earning person shouldn't give. You have your *tempo* (small bus) and you have to drive that.' I told him not to give and decided to give myself."

In many cases, a male donor is culturally conceived as an economic sacrifice. But in some situations, such as when a brother gives to a brother, it is framed as an economic investment. For example, one patient explained that his family has never been economically stable, and for the surgery they sold all of their land except the house. His brother, the donor, left his job in India to donate, placing great economic strain on the family. The donor echoed these concerns, saying his wife tried to discourage him from donating and sacrificing the money he would earn from his job in India. But the donor justified his donation by saying that after the surgery his brother, the recipient, will be able to earn more money and take care of the family. He explained that his brother is well educated and will easily find a more lucrative job. This situation reveals a sense of short- and long-term economic rationalization: one brother sacrifices his ability to earn in the short-term to save the life of a brother who will, in the long-term, be able to make even greater contributions to the family.

It is important to consider how both caste and class inform the economic value of women's and men's work within a family as both relate to the circumstances of organ donation. While caste has been, and continues to be, a major factor in determining "sociocultural experience," class has emerged as an additional source of social organization and determination (Liechty 2008: 5). In her ethnography of a Nepali hill village, Cameron found caste and class to be directly associated, where high caste families enjoy higher economic status than low caste families (Cameron 1998). Cameron observed that low caste women have relatively greater equality, autonomy, and power in their households than higher caste women, in part because of their economic contribution to the family (Cameron 1998). In contrast, high caste families place a higher value on women's domestic and reproductive labor, but, possibly because of the family's higher economic status over all, there are limited opportunities for a woman to financially contribute to her household (Cameron 1998). Thus, high caste families, and

high-caste women in particular, often maintain a greater economic dependence on men.

In the context of transplantation, this translates to a higher value placed on the health of men in high caste families. This would, in part, explain the importance of seeking treatment for male patients, as well as the perceived risks of men donating. In low caste families however, where women are more likely to be valued economic contributors, the family's entire economic status does not depend on men alone. In these families, we would expect that the health of men specifically is less of a concern than overall socioeconomic wellbeing of a family. Indeed, the patients, donors and family members we interviewed seemed to reflect these patterns. No Dalit or Madeshi participants mentioned concerns connected to "men as money makers" or "worries about men giving." In contrast, Bahun, Chhetri and Janjati families did mention these domains, three, ten and six unique times, respectively. This supports the assertion that the economic value of women is highly dependent on caste and, perhaps to a lesser degree, ethnicity. Furthermore, it suggests that the motivations for providing transplants to male patients and the reluctance to use male donors is also tied to caste.

While class and caste are often intertwined—lower caste individuals and communities are also, often, more economically disadvantaged than higher caste people—gendered motivations for transplants can also be drawn along class lines. Families in the two highest income quartiles were more likely to mention "men as money makers" and "worries about men donating" than were families in the lowest two income quartiles. Again, this suggests that in higher-class families there is an urgency to facilitate transplants for men and a fear of men donating, perhaps because families are structured such that economic stability is dependent on men. Conversely, in lower class families the economic concerns about transplant are less gendered.

Despite the focus on the economic value of men, it would be erroneous to suggest that the domestic and reproductive work of women, particularly high caste and high-class women, isn't valued. Indeed, our informants frequently brought up concerns about women being incapable of working during and following donation. Families of female donors worried about childcare, housework, and caring for the transplant recipient. But families are able to find ways to make up for the woman's absence while she is donating and recovering. For example, parents or in-laws take care of children, and older children are responsible for feeding their siblings.

Conclusion: Gendered Vulnerability and Dependence

Our research shows that women struggle to find a donor for variety of reasons, all of which are related to the patient's role and position as a female. The stories of our informants suggest that women, more than men, are obliged to suffer for the benefit of the greater family. Such findings are consistent with observations in Nepal and elsewhere in South Asia that women and girls are denied treatment more frequently than their male relatives (Pandey et al. 2002; Gupta 1987; Chen 1981; Leone, Matthews, and Dalla Zuanna 2003; Pokhrel et al. 2005; Karki 1988). As discussed in a paper on child healthcare in Nepal, gender affects all steps in a family's health seeking behavior (Pokhrel et al. 2005). It is clear that the limited access to treatment afforded to females is not unique to ESRD and transplantation. What is unique, however, is the directly tangible role other family members play in granting or denying this access. Beyond providing financial resources or investing time in seeking treatment, transplantation requires a relative to make a physical and intimate commitment—the removal of an organ—to the patient. And while women routinely make this sacrifice for men, men rarely reciprocate.

Despite our informants' diverse backgrounds and situations, a major theme in our data was the vulnerability of women and their dependence on men. To greatly simplify these patterns: women give kidneys because they are dependent on their husbands and men get kidneys but rarely give them because their health is viewed as more important to the family's economic stability. When discussing the findings from our research with Nepalis, both those working in the healthcare field and others, they, without fail, referenced "our male-dominated society." Despite the truth of such an assertion, it risks denying women any agency in the decision-making processes surrounding transplantation.

This research rejects the notion that all, or even most, wives donate kidneys to their husbands because they are overtly coerced or are victim to the control of more powerful members of their families. Rather, women make thoughtful decisions that seem to serve their best interest. From their own perspective, by donating kidneys to their husbands, women are asserting some control and some choice over their lives and the fate of their families. The irony is that this empowerment is both necessitated and limited by Nepal's patriarchal society. It is their vulnerable position that demands that women take such drastic measures to act in self-protection. A man's position with respect to organ donation is decidedly different, as we have

shown. Simply put, the livelihood and wellbeing of a man is not dependent on the survival of his wife. Men, therefore, are not motivated to donate organs out of a sense of self-protection. The result is a dearth of husbands interested in donating kidneys to their wives, which contributes to the extreme gender bias in transplantation in Nepal.

The Human Organ Transplant Center and Aarogya Foundation have made improving this gender bias a top priority. One of the ways they are attempting to do so is through a subsidy program for male to female donations in which the family of a male donor who gives to a female relative receives NRs. 50,000 (about \$500 USD). However, the root causes of the gender bias are deeply related to Nepal's systematic, inequitable treatment of women. Policies such as the limitations on obtaining Nepali citizenship through Nepali mothers (currently a subject of great discussion in the wake of the 2015 Constitution) both contribute to and are created by a culture of exclusion and discrimination.

Other studies on gender inequities in healthcare note that this issue does not have a straightforward solution. As Chen et al. write:

... simplistic policy prescriptions, such as increased female education, are not likely to remedy this fundamental problem, reinforced as it is by both perceived economic reality and strong cultural tradition. Rather, it seems likely that fundamental structural changes in the role, status, and economic value of women in the society will be required, in addition to alleviation of the economic poverty confronted by most of these families (1981: 67).

In the case of transplantation, women are not just denied healthcare, they are also seen as socially responsible for the health of their male kin. This unique aspect of transplantation highlights the multitude of factors that create a gender bias in healthcare more broadly in Nepal. As the prevalence of chronic diseases increases and the quality of medical care in Nepal improves, a comprehensive approach that considers kinship, social organization, obligation, gender roles, poverty, healthcare access, and development is necessary to work toward greater equity in organ donation—and to the value of the lives sustained through these operations.

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Endnotes

1. The massive numbers of Nepali men migrating for foreign employment is well documented (Gurung 2012; Adhikari 2015). Studies of men from other South-Asian countries observe that migration is associated with an increased risk of chronic diseases such as diabetes and hypertension which are known to cause ESRD (Shahul Hameed et al. 2013; Montesi, Caletti, and Marchesini 2016). Out-migration and subsequent health problems may be a significant factor in the incidence of ESRD in Nepal, however this has not yet been studied.

2. Participant annual household income ranges within quartiles (USD):

≤25 percentile	\$831-\$1,938
>25-50 percentile	\$2,326-\$2,492
>50-75 percentile	\$2,769-\$5,538
>75 percentile	\$6,646-\$11,077

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