

**TRAFFICKING IN PERSONS FOR THE REMOVAL OF ORGANS IN INDIA:**  
EXPLORING THE IMPACT OF ECONOMIC, SOCIAL, AND CULTURAL  
FACTORS ON VULNERABILITY AND PROTECTION

By

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This dissertation explores how influences on the individual, family, community, and governmental level impact susceptibility to trafficking in persons for the removal of organs (TPRO) in India. Two of the research questions examine specifically what impacts vulnerability and protection among a sample of 43 individuals living in a community in India. The third research question explores the role of the living organ donor assessment process in the prevention of trafficking.

In this dissertation, the theoretical understanding of how choices are made, or not made, particularly by vulnerable individuals, is explored. Qualitative interviews were conducted with persons trafficked for organ removal and persons not trafficked for organ removal who are living within the same socio-economic environment, but who were not all trafficked for organ removal. Study data were analyzed using constructivist grounded theory methods. Findings from this study show that economic, cultural, and social influences affect both protection from and susceptibility to trafficking. It was found that resources, government response to poverty, motivations, and the utilization of the body as an economic tool all influence trafficking status. Additionally, it was found that cultural and social influences included gender, family dynamics, awareness and community information sharing, and organ sale broker presence. Furthermore, trafficked persons secure government approval for organ removal through broker facilitation and the donor

assessment often fails to protect against of persons for organs. Findings reveal that family pacts against organ sales, knowledge of negative consequences of transplant, and protect individuals from being trafficked for an organ.

For those who were trafficked, it was found that the combination of poverty, coupled with the presence of organ brokers who work within an inadequate donor assessment system t created an environment where poverty originated organ removal (POOR) occurs. Both trafficked and non-trafficked individuals utilized their bodies in the way that they could to survive or meet financial obligations, as the environment requires it. This structurally coercive environment leads to trafficking of individuals for organ removal through the abuse of the individual's vulnerability. This research provides macro to micro level recommendations for the elimination of TPRO through preventative programs and policies, as well as highlights the need for assistance for trafficked persons.

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## **Chapter 1. Introduction**

Medical advances in organ transplantation have prolonged life and increased quality of life for many people worldwide, but often at the cost of others' well-being. With the rising incidence of chronic kidney disease (CKD), the demand for kidneys is far outgrowing the supply available globally, thus creating a market that generates a demand for organs for compensation. Commercial living organ donation involves an individual having an organ removed for material compensation. An illegal practice in all nations except one, Iran, commercial living organ donation promises the organ donor a benefit of compensation and for the recipient the benefit of an organ replacement. Existing literature, however, paints a dimmer picture of the practice, suggesting that the costs outweigh the benefit of compensation for the donors.

Chronic kidney disease has become a global health concern, as diabetes and hypertension rates in developed and developing nations are increasing (Jha et al., 2013; Noel, 2012). The National Kidney Foundation (2015) estimates that 10% of the population worldwide is affected by CKD; researchers estimate that the prevalence of CKD worldwide is between 7.2% to 35.8% depending on the age of the individual and the estimating equations used (Couser, Remuzzi, Mendis, & Tonelli, 2011; Jha et al., 2013; Zhang & Rothenbacher, 2008). Dialysis is one treatment option for patients with CKD. With the first deceased and living donation transplants being conducted in the mid-twentieth century (National Kidney Foundation, 2014), transplantation has become another treatment option for those with CKD.

Global data from 104 countries suggest that 100-120,000 solid organ transplants, including kidney, liver, and other organs, occur annually (Global Observatory on

Donation and Transplantation, 2014; WHO, 2008). The World Health Organization (2012) estimates that approximately 10,000 commercial transplants occur annually, the majority are kidneys. Increasing rates of CKD (Hill et al., 2016) and a shortage of deceased organ donors globally (Rudge, Matesanz, Delmonico, & Chapman, 2012) have both increased the need for organs, particularly kidneys, and have contributed to the occurrence of organ sales. Despite the benefits, the advent of organ transplantation has brought with it negative consequences, specifically the development of a global kidney market. In fact, the kidney is the most commonly commercialized organ, accounting for 75% of all organ sales around the world (Noel, 2012). This growth of organ sales can partially be attributed to the inadequacy of donation programs (Akoh, 2012).

Globally, the conceptual and ethical foundation that organ donation is built upon requires an individual to exercise his or her right to freely choose. This decision, based on personal preference and free will, is the cornerstone of organ donation movements around the world. Organ procurement organizations have historically depended on altruistic individuals to supply a viable organ, either as a living donation or after the donor's death. A systematic review indicates that the decision is impacted by various factors including relational ties, religious beliefs, and cultural and family influences (Irving et al., 2012). Family-level factors include family member belief in the importance of organ donation, or fear and medical mistrust, particularly related to ambiguity regarding brain death (Ralph et al., 2014). Social and cultural factors in some parts of the world, however, present challenges to public health campaigns that aim to increase altruistic donation when organ removal may not be the cultural norm (Bruzzzone, 2008; Concejero & Chen, 2009; Lock, 1999). These factors can greatly influence the donation rate in a particular

country. Research conducted in Japan indicates that the conceptualization of brain death and the tendency against living-related donation impact organ transplantation practices (Lock, 1999). In India, the lack of awareness and faith in the healthcare system, as well as religious beliefs and superstitions, are the primary reasons for a low donation rate (Panwar et al., 2016, Seth et al., 2009). To illustrate, a study of college students in India indicates that religious beliefs impact an individual's knowledge and attitude, with reported low levels of positive attitudes regarding transplantation and organ donation (Chakradhar et al., 2016). Researchers observed differences in study participant attitudes toward organ donation based on their religion, with Hindu belief in life after death cited as a factor in their lower level of support for organ donation (Chakradhar et al., 2016). For these individuals, despite their level of education and occupation, there were low levels of positive attitudes, pointing to cultural differences that impacts views on organ donation.

Awareness of donation efforts is limited (Wig, Gupta, & Kailash, 2003).

Although awareness has been increasing in India, there is a need to educate the public about the role of organ donation, particularly deceased donation (Mohan Foundation, 2016; Singh, Prasad, Bhandari, Bhilwar, & Badhan, 2016). The donation rate in India is 0.34 per million population (Mohan Foundation, 2014), as compared to the United States which has 26 donors per million population (National Transplant Organization, 2012). Interestingly, of the transplants conducted in India from 1971 to 2013, living donations accounted for 96% of the total transplants (Indian Society of Organ Transplantation, 2014). In the United States from 1988 to date, 43% of all organ donors have been living donors (OPTN, 2017).

With the rising incidence of CKD and low donation rates globally (Panwar et al., 2016; Singh et al., 2013), the demand for kidneys has long outpaced the supply available, specifically in India, thus creating a market for commercial donation from nationals and transplant tourists across the globe who have come to India for an organ. As demand exceeds supply globally, methods for organ procurement have arisen through alternative medical markets (Rudge, Matesanz, Delmonico, & Chapman, 2012). Individuals with resources can bypass traditional channels to find an organ by eliciting the help of illegal transplant tourism companies and brokers in their home country to find suitable donors in other countries who will receive compensation for their kidneys. The brokers facilitate communication between the donor and the recipient, as well as coordinate with hospitals and medical professionals. Complex networks exist that can link medically desperate recipients with financially desperate and vulnerable individuals whose individual or family survival often depends on the promised compensation (Danovitch et al., 2013).

Given the imbalance in supply and demand, commercial kidney transplants that occur globally are conducted illegally. Iran is the only nation that has a formal legalized structure for a paid “donation”, allowing individuals to consent to the sale of their organs and receive payment upon removal (Ghods & Savaj, 2006; Hamidian, Fry-Revere, & Bastani, 2015).

There is an ongoing debate regarding the ethical appropriateness of the legalization of organ sales. Pro-legalization advocates point to the potential for additional lives to be saved, as the supply of viable organs would increase (Erin & Harris, 2003; Gregory, 2011). Advocates also explain that a regulated trade would reduce incidences of violence (Gregory, 2011). Conversely, an increase in exploitation of vulnerable

individuals could occur as the result of legalization, as only the most vulnerable will sell their organs (Adair & Wigmore, 2011). Individuals who must sell their organ to survive will remain limited in their choices and will be compelled by their vulnerability to sell their organ. In Iran, about 70% of individuals who sell their organs are poor (Hippen, 2008).

Despite debate, paid donation is illegal in the United States and was banned in 1984 under the National Organ Transplant Act (Pub. L. 98-507). This act prohibits the sale of organs and ascribes penalties for individuals who engage in the acquisition, receipt, or transfer of human organs when payment is involved (National Organ Transplant Act, 1984). In India, according to its Transplantation of Human Organs Act (THOA) of 1994, organ sales are similarly illegal (Transplant of Human Organs Act, 1994). The purpose of THOA is to regulate the removal, transplantation, and storage of human organs and to prevent their commercialization (Transplant of Human Organs Act, 1994). THOA was amended in both 2008 and 2011 to include a greater emphasis on organ transplantation through deceased donation (Ministry of Law and Justice, 2011).

Regardless of the initial law and its subsequent amendments, India has been identified as a country where organ sales commonly occur (Budiani-Saberi et al., 2014; Goyal et.al, 2002; Jha, 2004; Shimazono, 2007). Beginning in the late 1980's through the present, commercial transplants are common practice in India, with Indian nationals and foreign transplant patients seeking to purchase a kidney (Budiani-Saberi et al., 2014; Jha, 2004). The number of commercial transplants that occur in India annually is unknown.

Existing literature, to be discussed in-depth in Chapter 2, indicates that organ sales continue to occur in India through the exploitation of vulnerable populations

(Budiani-Saberi et al., 2014; COFS, 2014). Existing literature suggests that commercial living donation is an exploitative practice that is rife with ethical complications and challenges (Budiani-Saberi & Delmonico, 2008; Campbell, 2016; Danovitch & Al-Mousawi, 2012; Epstein, 2009; Gallagher & McAdam, 2013; Greasley, 2012; Jha, 2006; Scheper-Hughes, 2000; Scheper-Hughes, 2015). It is the poor and desperate who become involved, as brokers often identify vulnerable individuals and provide them temporary solutions to their financial struggles. With this practice continuing in India, it is critical to understand the donation process, examine what contributes to its occurrence, and to ultimately develop solutions to curb the practice.

### **Research Questions**

The primary aims of this study are to identify influences that both make individuals susceptible to, or protect them from being trafficked for the removal of kidneys. These influences are economic, cultural, societal, familial, and individual. The specific research questions are:

- What are the life circumstances or factors that make individuals vulnerable to being recruited to sell an organ?
- What factors protect individuals from having an organ removed for compensation?
- Does the living donor assessment process serve as a mechanism to protect individuals from kidney sales?

### **Conceptual Framework**

This study will focus on individuals who are living in a specific community in

Northern India. To compare experiences of those who have received compensation for their kidney (*persons trafficked for organ removal- PTOR*) and those who have not (*not persons trafficked for organ removal-NPTOR*), despite similar living conditions and socio-economic statuses, two distinct groups of participants will be recruited. (Note: the rationale for the choice of PTOR and NPTOR will be discussed later in this chapter.)

Participation from these two groups of individuals is necessary to answer the research questions and to understand both how trafficking in persons for the removal of organs (TPRO) occurs and what specifically makes individuals susceptible to it. This study explores the specific influences that contribute to the likelihood that an individual becomes a PTOR. For the purpose of this study the term *organs* is used to refer to kidneys.

### **Understanding vulnerability and consent**

The concept of vulnerability is generally discussed in terms of the protection of vulnerable populations. Vulnerability can broadly be understood as a state of increased risk of harm and lessened ability to protect oneself from harm (Rogers, Mackenzie, & Dodds, 2012). The United Nations/International Strategy for Disaster Reduction (UN/ISDR) (2004) defines it specifically as, “conditions determined by physical, social, economic, and environmental factors or processes which increase the susceptibility of a community to the impact of hazards” (p.16). There is not one agreed upon conceptualization of vulnerability, but global scholars continue to discuss how vulnerability impacts susceptibility to experiences and explore various approaches to identifying risk and measuring vulnerability (Birkmann, 2007; UN/ISDR, 2004). Work has been done to characterize and describe the type of vulnerability.



O'Neill (1996) named two types: persistent, as the vulnerability that exists from being a human, and selective, as the vulnerability that arises due to certain circumstances. For example, selective vulnerability may be present based on the life choices of the individual. This distinction has been criticized by scholars citing the challenges in the implications.

Offering a different conceptualization on the types of vulnerability, Kipnis (2003) developed seven categories of vulnerability, in the context of pediatric human subject research, that help to further refine the definition of vulnerability. The seven categories of vulnerability are incapacitational, juridic, differential, social, situational, medical, and allocational (Kipnis, 2003). Some explain how vulnerability arises from human characteristics, such as age or medical condition, whereas others exist as a result of unequal systems and the social devaluing of individuals from a particular group. Intrinsic vulnerability refers to individual characteristics, such as gender or age, whereas extrinsic vulnerability is outside of the individual, for example poverty factors in a community that impact vulnerability. While this categorization was developed in a different context and for a different purpose, the framing of vulnerabilities as either intrinsic or extrinsic is helpful in examining the intrinsic and extrinsic types of vulnerability.

In another perspective, Birkmann & Fernando (2008) explain that vulnerability has two key components: susceptibility and coping capacity. Both are of interest in this study, as susceptibility to TPRO can be mitigated by protective factors, or coping capacity. While most vulnerability studies focus solely on susceptibility (Birkmann & Fernando, 2008), the coping capacities of people should not be ignored because they are critical components to understanding vulnerability.

Furthering the discussion, vulnerability as a concept is often linked to autonomy and an individual's diminished self-determination, where an individual's ability to provide consent may be compromised due to his/her sense of free will. Informed consent requires that individuals can assert their agency to make their own independent choices, free of coercion or undue influence (Belmont Report, 1979). The consent process is used to ensure an individual is freely choosing to participate, or not, in a research study with knowledge of benefits and risks of participation, or in this case, donate their organ, free of pressures and exploitation.

The Belmont Report is a document developed by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research that summarizes the ethical principles for research involving human subjects (1979). The Belmont Report (1979) lists the three necessary elements for informed consent as “information, comprehension, and voluntariness.” When making a decision, an individual must have all pertinent information, the ability to comprehend the information, and then be able to make an autonomous decision based on the information, free of influence from others. While all three are relevant to research, the examination of voluntariness is particularly critical, as it relates to the validity of consent that was obtained from individuals whose vulnerability negatively impacted their decision making. For example, an individual's ability to provide informed consent for organ removal could be impacted by his/her economic status, as the financial hardship was the motivating factor in the decision; the validity of consent is altered by the circumstances in which the consent was obtained. An expanded discussion of consent and TPRO, as it relates to study protocol, is provided in Chapter 8.

## Terminology and International Understanding

Since the practice of compensation for organs was first brought to light, international organizations and researchers have worked to develop definitional understanding of organ trafficking. The United States does not formally recognize organ trafficking as a form of *human trafficking* in its domestic counter-trafficking legislation. The United Nations, however, defines trafficking of a person for the removal of organs (TPRO) as one form of trafficking in persons, among other forms of trafficking including for sex and labor (Chatzis & Albert, 2015; United Nations, 2000). In 2000, the United Nations adopted the Protocol to Prevent, Suppress, and Punish Trafficking in Persons, especially Women and Children (United Nations, 2000). Its purpose is to prevent and combat trafficking of persons and protect and assist victims of trafficking (Article 2, par. a, b). This protocol, referred to as the Trafficking Protocol, or the Palermo Protocol, defines trafficking in persons as the use of threats, coercion, abuse of an individual's position of vulnerability, and/or the giving or receiving of payments or benefits to achieve control over another person for the purpose of exploitation (Article 3, par. a). Within the definition there are three specific elements: the act, the means, and the purpose, all of which must be present to argue a case of trafficking in persons. Ratified by 159 nation states, the Trafficking Protocol serves as the first international agreement that addresses organ removal as a form of human trafficking.

Consent and compensation are two additional issues that must be addressed when examining TPRO. Consent is addressed in the Trafficking Protocol and is described as “irrelevant” when elements of trafficking in persons, as described above, are present (Article 3, par. b). The consent that is obtained from an individual is rendered invalid

when threats, coercion, or abuse of an individual's vulnerability were used to obtain consent. The Protocol also addresses payments by noting that the receipt of payment for an organ does not mean that the organ removal was not exploitative (Article 3, par. a). Persons trafficked for organ removal, despite receiving payment for their kidneys, are still classified as victims of human organ trafficking according to the Protocol.

Following the approval and subsequent ratifications of the Trafficking Protocol, the international transplant community gathered to address human trafficking of organs. On April 30, 2008, in response to increased journalistic accounts and growing concern from the World Health Assembly and other relevant organizations, a meeting was convened in Istanbul by the Transplantation Society of the United States and the International Society of Nephrology to address the growing epidemic of organ and tissue trafficking. Over 150 government officials, social scientists, and ethicists, representing the scientific and medical bodies from 78 countries, convened in Istanbul, Turkey. Their work culminated in the Declaration of Istanbul on Organ Trafficking and Transplant Tourism (Declaration of Istanbul, 2008), the document that iterates the collective opinion of the scientific and medical communities. It provides clear definitions of inappropriate practices, discusses the key ethical principles related to the problem, and outlines actionable proposals and suggestions for meeting the corrective goals of the Declaration.

**Establishment of definition.** A specific definition of organ trafficking was established in 2008 as a part of the Declaration of Istanbul based on Article 3a of the Trafficking Protocol (Declaration of Istanbul, 2008). *Organ trafficking*, according to the Declaration is defined as:

The recruitment, transport, transfer, harboring, or receipt of living or deceased persons or their organs by means of the threat or use of force or other forms of

coercion, of abduction, of fraud, or deception, of the abuse of power or of a position of vulnerability, or of the giving to, or receiving by, a third party of payments or benefits to achieve the transfer of control over the potential donor, for the purpose of exploitation by the removal of organs for transplantation (p.3)

Following the development of this definition, debate began on whether to describe the practice as trafficking in human organs or trafficking of persons for organ removal. Trafficking in human organs in description is distinct from the trafficking of persons for organ removal. The Joint Council of Europe and the United Nations (2009) released a report that delineated the international understanding of both trafficking of organs and trafficking of humans for the purpose of organ removal.

As a result, international health and human rights organizations, most notably the Coalition for Organ-Failure Solutions (COFS), began referring to the practice as human trafficking for organ removal and later to trafficking in persons for the removal of organs. This was useful in situating the practice as a human trafficking abuse within the United Nations Trafficking Protocol and within a human rights framework (COFS, 2014; Ezeilo, 2013).

In October 2013, Joy Ngozi Ezeilo, the United Nations-appointed Special Rapporteur on trafficking in persons, presented her findings to the General Assembly. In her report to the United Nations, she presented a counter argument to the conceptualization of the practice as “trafficking in human organs” by the Council of Europe, arguing that the definition was not helpful, as it did not serve victims’ rights and did not frame the practice in terms of protection of trafficked persons (Ezeilo, 2013). She also formally labeled the practice as a form of trafficking in persons, and highlighted opportunities for member states to intervene and leverage established international legal frameworks for prevention (Ezeilo, 2013). The presentation served to remind member

states of their legal obligation to prevent the practice, prosecute the offenders of trafficking, and protect and assist the victims. This report serves as a foundation for ensuring that governments, in collaboration with non-governmental and community organizations, provide basic welfare to individuals to not only assist victims, but to prevent additional cases of trafficking. The Coalition for Organ-Failure Solutions notes that this report is particularly relevant in India, as poverty has been linked to trafficking status in the research (COFS, 2014).

During this time, many global organizations, including the United Nations, were simultaneously debating the use of the two terms, trafficking in human organs and trafficking of persons for organ removal. The Council of Europe created the Convention against Trafficking in Human Organs that sought to explain the practice as “trafficking in human organs” and included provisions for deterrence (Council of Europe, 2014).

Another addition to the international dialogue was a report released by the Organization for Security and Co-operation in Europe (OSCE) titled *Trafficking in Human Beings for the Purpose of Organ Removal in the OSCE Region* (Shin & Orfano, 2013). The OSCE region includes countries across the globe, but primarily in North America, Europe, and Asia. The report includes an analysis of cases of criminal proceedings in 10 countries. The report primarily focused on what is currently occurring on a global context, how this form of trafficking in persons operates in the OSCE region, and who the participants are including recipients, recruiters, medical professionals, and persons who were trafficked. One of the contributions of the report that is relevant to this study is the discussion of how to address the rights and needs of the victims, particularly how to examine the issue through a rights-based framework.

Following these reports, the United Nations Office on Drugs and Crime (Chatzis & Albert, 2015) released an assessment toolkit entitled *Trafficking in Persons for the Purpose of Organ Removal*. The purpose of this toolkit was to provide definitions as described in the Trafficking Protocol and other legal instruments, and to further explain how the practice differs from trafficking of organs. The portion of this report that is most relevant to this study is the discussion of consent, as consent is understood to be irrelevant in circumstances where the vulnerability of the individual impacted the organ removal decision (United Nations, 2000). Additional reports exist that contribute to the conceptual understanding of the issue, and emphasize how terminology shapes the framing of the issue within the international trafficking contexts (Shin & Orfano, 2013; UNODC, 2008).

**Study terminology.** Variability in use of terminology to describe the practice exists in the literature. For the purpose of this study the term *person trafficked for an organ removal* (PTOR) will be used to describe individuals who have been exploited for organ removal. The practice of recruiting an individual for the removal of his or her organ, as described throughout the study protocol, will be referred to as *trafficking in persons for the removal of organs* (TPRO). This term is consistent with the current language that is used to explain this practice (Ezeilo, 2013), as described above. This term is appropriate because it recognizes the practice as a form of trafficking in persons and frames it as a human rights abuse. During the data collection phase of this study, the terms *commercial living donor* and *commercial living donation* were used to facilitate researcher neutrality. The choice to use specific trafficking and human rights-based

terminology for the dissertation was made to appropriately situate the research within international legal and human rights frameworks.

### **Theoretical Basis**

As previously described, understanding trafficking for the purpose of organ removal (TPRO) requires theoretical and conceptual exploration. Central to the discussion of TPRO is choice and the examination of how choice or lack of choice impacts trafficking status. In an effort to tease out the concepts that guide the theoretical discussion of *choice*, a combination of both specific concepts and theories will be examined. Unitary Assumption Theory (UAT) is examined and then critiqued for its relevance to decision making (Becker, 1976). UAT explains how decisions are made on the household level (Becker, 1976). The shortcomings in the UAT are then explored further by introducing Vulnerability Theory broadly, with the role of vulnerability and protection considered (Zakour & Gillespie, 2013), as well as the concept of the Abuse of a Position of Vulnerability (APOV) (Gallagher & McAdam, 2013). Separate from Vulnerability Theory, but related, APOV is utilized to examine the means by which vulnerability is abused as a means of trafficking (UNODC, 2013). The individual trafficked person's beliefs in his/her autonomy and role in the decision-making process further complicate the understanding of choice and autonomy (Deci & Ryan, 1985). Self-determination theory, as it explains choice and autonomy is explored. This specific combination of concepts is provided to fully describe what drives an individual's decision to have an organ removed.

**Unitary assumption theory.** Unitary Assumption Theory explains how households function and particularly how decisions are made by members of the



household is the Unitary Assumption Theory (Becker, 1976). The theory, also referred to as the common preferences model, the altruistic model, or the benevolent dictator model, explains the distribution of tasks and goods. A household within this framework acts as a single decision maker and it is assumed that the household's interests are one. The feature most important to this study is the existence of a household welfare function, a way of decision making that reflects all its members (Becker, 1976; Sen, 1997). Plainly stated, decisions are made by a member of the household, the altruist, to benefit everyone within the household. Examining TPRO through a UAT lens, one may understand that the choice to sell a kidney was simply that, a choice that was made by a member of the household to benefit all members. For example, a family struggling to obtain food daily may benefit from the choice of a single decision maker making a decision on behalf of the entire family, because the end result may be food stability. The decision that is made by the individual is for the benefit of the entire household. Void of other factors and constraints, UAT could explain how decisions are made on a household level with regards to TPRO.

Development economists have sought to highlight the problems within UAT. The crux of the problem for some scholars with this theoretical framework is that the benefit of others may not be the motivation, and equal sharing of household resources may not always be the norm (Chiappori, Haddad, Hoddinott, & Kanbur, 1993; Falkingham & Bashcieri, 2009). Decisions that are made by the head of the household may not be for the benefit of the full household. The assumption that the head of the household is altruistic does not account for cases in which the presumed altruist also perpetuates violence and/or neglecting the well-being of others (Haddad, Hoddinott, & Alderman,

1994). Additionally, external factors, including gender and culture, have been cited as limitations to the model, with scholars specifically noting that there are different preferences within a household (Chiappori et al., 1993; Falkingham & Bashcieri, 2009). For example, families may see themselves as collective decision making entities, as opposed to unitary (Chiappori et al., 1993).

**Disaster vulnerability theory.** Disaster vulnerability theory focuses on both the *risk* and *protective* factors of individuals and social systems (Bonanno & Gupta, 2009). Risk factors, also referred to as liabilities, are characteristics that impact individual, group, or community susceptibility to disaster. In the case of disaster, the root cause of vulnerability is described as a combination of liabilities that may include gender, lack of resources, location of residence, political infrastructure, poverty, race and ethnicity, hunger, or community violence (Blaikie, Cameron, & Seddon, 1980; Bolin, 2007; Zakour & Gillespie, 2013). These risk factors can be described as social, economic, and political influences that impact vulnerability.

For example, a vulnerability analysis of two tsunami affected communities in Sri Lanka indicates that specific risk factors exposed individuals and families to more harm pre and post disaster. Birkmann and Fernando (2008) explain that within the study there were specific vulnerability indicators (i.e. gender). When examining the number of dead and missing following the tsunami, the number of females dead or missing was significantly higher than males. For example, in the community of Galle, 35% of missing were male and 65% were female (Birkmann & Fernando, 2008). It is theorized that this was likely the result of the women's inability to climb on the roof in time to be safe or an inability to leave to swim away due to their role of tending to household duties and/or

never needing to climb or swim (Birkmann & Fernando, 2008). Gender groups experience vulnerability differently, and in this specific community, clearly gender played a role in the likelihood of death from tsunami.

Additional studies that have been conducted in Indonesia and India also suggest that gender is a vulnerability indicator (Guha-Sapir, Parry, Degomme, Joshi, & Arnold, 2006; Rofi, Doocy, & Robinson, 2006). Specifically, women have suffered more consequences as a result of disasters than men. In one particular study, gender is listed as a risk factor in disasters, along with other factors that increased risk of vulnerability including age, socio-economic status, and level of preparation/warning (Guha-Sapir et al., 2006).

Conversely, protective factors, or capabilities, are described as social, economic, physical, and environmental factors that reduce vulnerability to disaster. Capabilities may include social networks, access to services, disaster prevention strategies, the natural environment, political or societal influence, and economic opportunities (Zakour 2008; Zakour, 2010; Zakour & Gillespie, 2013). Protective factors, or coping capacities, were also examined in the tsunami affected communities. Land title/recovery and knowledge of the hazard were both identified as indicators of coping capacity. Households that owned land fared better than those who were squatters, with regards to repairing house damage (Birkmann & Fernando, 2008). Owning land allowed for quicker repair of homes, as land could be sold to purchase materials. It was also found that the understanding of the potential effects of the tsunami served as a protective factor regarding proactive planning and preparation for evacuation (Birkmann & Fernando, 2008).

Addressing social networks as protective factors, a study in Pakistan found that family-based social networks served as a protective factor in the aftermath of the earthquake in 2005. Kaleem, Safdar, and Ali (2016) explained that connection to social networks post-disaster helped to reduce the harm as a result of the earthquake. For example, the strength of a family-based network allowed for more planning and sharing of necessary supplies and equipment (Kaleem et al., 2016).

Risk and protective factors can be experienced as a whole community, on the family level, or at the individual level. A community's response to a disaster may be impacted by the social infrastructure and networks that exist. Whereas an individual's responses to disaster is dependent on their ability to utilize the social network as a protective factor. Individual situations also differ, and it is a combination of community and individual risk and protective factors that make an individual vulnerable to disaster. It is this unique combination of personal and societal factors that impact response to disaster, in particular an increase in vulnerability translates to an increase in susceptibility to the disaster. Zakour and Gillespie (2013) describe how vulnerability is not a result of poor personal or community decisions, but rather a result of the constraint of physical, social, and economic conditions, and personal situations. Lack of income and social status may also increase vulnerability as individuals or groups may lack resources or power to prevent and mitigate disasters. Individual and community factors are related because community vulnerability may contribute to individual vulnerability. For example, community vulnerability, such as the lack of living wage jobs, makes individuals and families economically precarious and vulnerable to coercion for income. The relationship between risk and protective factors for a community or an individual is

complex. While a community as a whole may be vulnerable to disaster based on the lack of resources, an individual may possess protective factors that reduce or eliminate their own susceptibility to that disaster.

The term ‘disaster, as previously described, could be the occurrence of trafficking in persons for the removal of organs. As the impact of a natural disaster on the individual or family may depend on the combination of risk and protective factors experienced, the vulnerability of the individual affects their susceptibility to the disaster of TPRO. Just as a natural disaster can lead to long-term economic, physical, and social consequences on multiple levels, individuals impacted by TPRO experienced similar, yet unique, consequences.

The risk factors that make an individual susceptible to TPRO can be understood as constraints, as described by Zakour and Gillespie (2013). Economic constraints, such as lack of stable work and work availability for women, are factors that increase both individual and community-level vulnerability. On the contrary, the protective factors, for example community awareness, may be an example where the utilization of a social network reduces susceptibility to the disaster, in this case TPRO. In addition, family level protective factors, such as family planning and preparation to respond to disaster, may decrease susceptibility.

**Abuse of a position of vulnerability.** With regard to trafficking, specifically for organ removal, scholars introduced the theoretical concept of Abuse of the Position of Vulnerability (APOV) (Gallagher & McAdam, 2013). As opposed to examining vulnerability solely as it relates to susceptibility to trafficking as previously discussed, the concept of APOV explains how an individual’s vulnerability is the *means by which*

*trafficking occurs* (Gallagher & McAdam, 2013). Within the APOV definition exists the explanation of how the individual's position of vulnerability was exploited to commit a crime, thus describing the individuals as victims of the crime. The consent of the individual in this instance is irrelevant because it was the use and abuse of the individual's vulnerability that led to the organ removal, not the decision of the individual trafficked person.

The removal of an organ occurs when a vulnerable individual is desperate due to a lack of resources and an absence of economic, social, or family level protective factors, and their desperation is exploitative. The presence of risk factors and the absence of protective factors combine to create a position of vulnerability that individuals experience. In these instances, those who facilitate organ sales, particularly brokers, utilize their knowledge of the community to identify particularly vulnerable individuals. The trafficked person's position of vulnerability is utilized as the means by which the trafficking of the organ occurs. The practice of TPRO would not occur without the existence of vulnerable individuals and the subsequent abuse of that vulnerability.

APOV asserts that the mechanism by which individuals become victims of trafficking is the abuse of their position of vulnerability. What complicates this understanding of "victimization" is the individual's view of him/her self as an autonomous decision maker, not as a victim. While APOV and the current international understanding of how the means by which trafficking occurs render consent irrelevant and negate the decision of the individual, it is necessary to explore theories that are contrary to this assertion.

**Self-determination theory.** Self-determination theory explains how individual decision making is self-motivated and self-determined (Deci & Ryan, 2000). A relevant concept from Self-determination Theory (SDT) is autonomy and the individual's innate desire to act in their own interests or exercise free will (Deci & Ryan, 1985). The labeling of those who have given their kidney for money as victims, due to the exploitation of their vulnerability, may be in stark contrast to their view of their role in the removal of their organ. Individual memory of the kidney removal may include their self-determined and self-described choice to do what they must for their family. Individuals may not view themselves as vulnerable victims, but rather as active players and decision-makers. It is important to recognize, however, that decisions were made under specific circumstances and that different circumstances would have led to different decisions.

### **Theoretical Exploration**

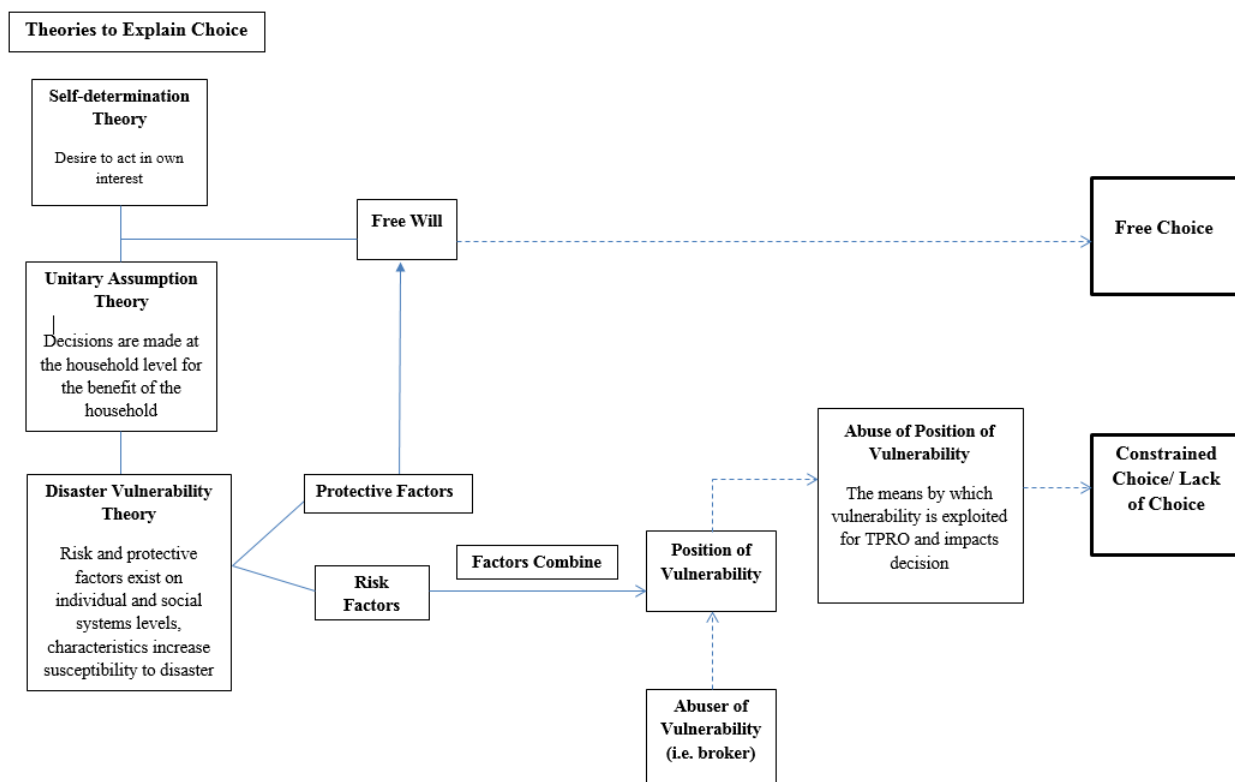
Choice, or more specifically, perceived choice, is a concept at the center of understanding how human kidney sales occur. This understanding even frames the ways in which the problem is described, commercial organ donation versus human organ trafficking. Depending on the degree of autonomy that is attributed to an individual regarding the specific act of selling an organ, the conceptual framework differs. For example, viewing the act of removing a kidney for profit through the lens of UAT might lead to the understanding that this problem can be explained by examining how individuals made a rational choice to offer their kidney for money. A kidney was removed for profit and the individual made the choice to have this organ removed. Examining this issue with a narrow view of choice and within this specific theoretical framework is particularly dangerous, as it places full onus on the individual

and does not recognize the ways in which other factors contribute. Economic, cultural, or societal influences may include socio-economic and work status, gender, acute familial stressors and time pressure, and both family and community-level awareness. These influences can be described as vulnerability or protective factors that impact response to trafficking in persons for the removal of organs. Economic opportunities, or the absence of these opportunities, can also influence an individual's "choice." However, only examining the protective and risk factors, and neglecting to address the economic and choice factors, particularly the autonomy of the individual, particularly through the lens of Self-Determination Theory, also fails to explain the theoretical underpinning of the decision making process.

Figure 1 below illustrates the theories and theoretical concepts introduced and how they relate to choice. On the left side of the figure are the three theories that were introduced. Self-determination theory (S-D), as previously described, explains that individuals make choices that are in their own interest, which is an expression of their free will. This expression leads to a free choice. Unitary Assumption Theory (UAT) assumes that decisions are made at the individual level for the benefit of the household, within an environment where rational, free choices are made.

Disaster vulnerability theory, an additional theory shown in Figure 1, explains that factors exist of multiple levels that impact susceptibility to disaster. As seen in the figure, factors can be either risk inducing or protective. These factors combined to a position of vulnerability and an abuser of vulnerability uses this position and this leads to the abuse of the position of vulnerability (APOV).



**Figure 1. Choice and Theory**

## **Chapter 2. Literature Review**

An examination of available literature is critical to understanding how TPRO is understood around the world and in India. Existing studies have aimed to gain a general understanding of the motivation for donation, the process of trafficking in persons for the removal of organs (TPRO) and the effect of the practice on donors. To provide context, the donor assessment process for screening potential living donors is discussed globally and specifically in India. Then a review of international literature related to the issue is provided and arranged by theme, specifically donor motivation and post-transplant consequences. It is followed by a separate section that focuses exclusively on research studies that have been conducted in India. Themes related to TPRO in India are also explored. The information is presented by research studies conducted in India on TPRO in an effort to show the progression of knowledge development and increased topical understanding.

### **Living Donor Assessment Standards**

To become a living organ donor, one must be deemed physically and emotionally fit by the appropriate governing boards and professionals, depending on the country. Common practice internationally is to employ a formalized system for assessing the psychological, social, and physical well-being of potential living organ donors prior to approving organ removal (Duerinckx et al., 2014; Papachristou et al., 2004). The process for becoming a living organ donor is designed to be rigorous to ensure that the living donor is physically able, fully aware of all information, and able to make an autonomous informed decision prior to organ removal. The psychosocial and physical dimensions of living organ donation require that strict policies and procedures be employed to ensure

the safety and well-being of the living donor. Ensuring living donor safety and minimizing negative physical impacts on donors should be at the center of donor assessment processes and procedures (Dew & Jacobs, 2012; Dew, Myaskovsky, Steel, & DiMartini, 2013). In the United States, guidelines for the assessment of living donors who are not related to the recipient biologically or through a longstanding relationship have been developed by leading researchers, representatives from governmental agencies, and national transplant organizations (Dew et al., 2007; OPTN, 2016). The guidelines indicate that the risk and protective factors that influence the psychosocial outcomes of non-related donors must be examined (Dew, Jacobs, Jowsey, Hanto, Miller & Delmonico, 2007; OPTN, 2016). In addition, basic principles to guide the informed consent and evaluation process are being included in the development of living donor assessment guidelines in the United States.

Additional assessment tools have also been developed that are intended to aid transplant centers in the assessment of the physical and emotional well-being of the potential donor. Pham and colleagues (2007) outlined the main components in the evaluation of living donors which includes a psychosocial evaluation to start, followed by a medical evaluation, an assessment of risks, and finally a surgical evaluation. The psychosocial assessment should include an evaluation by a psychiatrist or mental health professional and address the protection of the donor's confidentiality, and assess the donor's mental and physical health (Pham et al., 2007). Assessment of donor motivation and the donor's ability to make an informed and non-coerced decision are also considered standard practice. An evaluation of any underlying psychiatric conditions, history of substance abuse, and the social and financial support systems of the potential living donor

are also reviewed (Pham et al., 2007). Psychological consequences, such as depression and resentment, should also be assessed. The components described are part of a core curriculum outlined for the use of transplant centers and medical professionals internationally, but are not always utilized as there is great variation in the psychosocial assessment process (Pham et al., 2007).

A systematic literature review of the psychosocial evaluation of living kidney and liver donor candidates indicates that there was variability in the consensus statements, guidelines, protocols, and programs reviewed (Duerinckx et al., 2014). The researchers included 34 peer-reviewed publications, seven guidelines, protocols for 21 programs, and six consensus statements from the United States, Canada, Australia, and European nations. Findings indicate that variability is observed in protocols and programs, the screening criteria for living donors are not evidence-based, and there is no operational definition of the necessary psychosocial status (Duerinckx et al., 2014). Furthermore, variation not only exists in screening criteria, but also in the methods used to conduct psychosocial evaluations.

Despite variation in screening criteria, consensus does exist in the literature, however, that any person who donates an organ should be free of coercion, competent, fully informed of the benefits and risks, and cleared medically and psychologically to donate (Abecassis et al., 2000; Adams et al., 2002; Dew et al., 2007; Olbrisch, Benedict, Haller, & Levenson, 2001; Reese, Boudville, & Garg, 2015; Transplantation Society, 2004). Of the literature included in the systematic review, 67% mentioned the importance of assessing for vulnerability, coercion, or pressure from family members or outside parties (Duerinckx et al., 2014). Regarding the U.S. non-related living donor guidelines,

special attention has been paid to the motivation of the non-related living donor as the donor must be free of manipulation, coercion, or undue solicitation (Adams et al., 2002; Dew et al., 2007). Examination of motivation focuses on the reasoning or the rationale of the living donor and the determination that the decision is free of coercion, incentives, or persuasions (Dew et al., 2007). Several ethical issues associated with living donation are noted in the donor assessment literature and provide further evidence of the need for improving donor assessment (Pham, Wilkinson, & Pham, 2007). One critical ethical issue is that health care professionals must ensure that the potential living organ donor is acting autonomously and this is done through the psychosocial assessment (Reese et al., 2015; Spital, 2001; Transplantation Society, 2004). Spital (2001) explains that in the informed consent process, the individual's understanding and freedom to make an autonomous choice are particularly important when assessing for living donation. The need to protect the living donor from exploitative forms of donation, such as commercial donation, has been emphasized in the literature.

### **Donor Assessment in India**

Receiving compensation for a living organ transplant in India is illegal and the government is charged with establishing structures and procedures to prevent the practice. In India, the responsibility of assessing potential living donors for psychosocial well-being and ensuring that individuals are donating an organ in spite of, and not because of, economic circumstances, was given to state-appointed members of Authorization Committees through the Transplantation of Human Organs Act (Transplant of Human Organs Act, 1994). Authorization Committees are charged with determining the vulnerability of potential living donors to coercion and ensuring that they are not

victims of human organ trafficking. Each state has one committee and that committee is comprised of state-appointed individuals who are not affiliated with the transplant center.

The law in India requires that a living donor be related to the recipient as a first-degree relative (e.g. parent, sibling, grandparent, or spouse) and that medical tests and appropriate paperwork be provided to establish this relationship (Transplant of Human Organs Act, 1994; Shroff, 2009). In the event that a first-degree relative is not available, a recipient and donor can seek special permission for the transplantation. A joint application is made by the recipient and the potential donor and the Authorization Committee makes a decision based on the application. A copy of the application form for approval of transplantation from a living donor is provided (Appendix E). The form requires the information, and photograph of the donor and recipient, as well as a signature attesting the truth of the statement that the “decision has been taken without undue pressure, inducement, influence, or allurements, and that all possible consequences and options of organ transplantation have been explained” (NOTTO, 2014). Instructions for applicants are included on the form. Most relevant to this study, potential donors and recipients are required to provide evidence of three years of income (NOTTO, 2014).

An interview is conducted to determine the motivation of the donor. The committee is charged with determining that the motivation for donation is purely out of altruism and affection, not monetary compensation (Shroff, 2009). Beyond the governing rules and the application process, little is known about how the donor assessment process functions in India.

Despite the passage of the Transplantation of Human Organs Act in 1994

(THOA), many cases of TPRO have been reported (Budiani-Saberi et al., 2014; Cohen, 1999; Goyal et al., 2002). The knowledge of an ongoing market in India suggests there is a disconnect between the regulatory procedures and the occurrence of commercial living donation. The application process requirement is circumvented by individuals who facilitate commercial organ transplantation. To be discussed in detail in Chapter 6, brokers assist in the preparation of necessary documentation for PTORs for gain approval for transplantation.

Scholars criticize the THOA for its inability to reduce commercial organ transplantation (Agarwal, Srivastava, Gupta, & Tripathi, 2012). The literature has not provided clear evidence about these inconsistencies and scholars have speculated that the disconnect is potentially due to various reasons. Shroff (2009) notes that misinterpretation of the law by transplant clinicians and Authorization Committee members may account for some cases of commercial donation.

### **Motivation**

Given continued commercial donation on the global and Indian-national level, an exploration of the motivation for this practice is critical. Interested in exploring the *why*, previous researchers have sought to understand what individual and community circumstances contribute to TPRO. Findings from studies conducted in various countries indicate that poverty and financial reasons, and hope for a better future, motivate individuals to sell kidneys (Awaya et al., 2009; Budiani-Saberi et al., 2014; COFS, 2011; Columb, 2016; Gatarin, 2014; Mendoza, 2010; Moazam, Zaman, & Jafarey, 2009; Moniruzzaman, 2012; Naqvi, Ali, Mazhar, Zafar, & Rizvi, 2007; Rizvi, Naqvi, Zafar, Mazhar, Muzzafar, & Ahmed, 2009; Yea, 2013). For example, in Bangladesh, individuals

who sold their kidney hoped for a brighter future. They expressed how hope for a better life, one free of the struggles of poverty, was their motivation (Moniruzzaman, 2012). Mendoza (2010) conducted a study in Columbia and the need for immediate money to repay debts or to support family members was the primary reason for organ removal in 91.4% of cases included. Journalists and non-governmental organizations have reported that individuals in Nepal who suffered loss due to the earthquake in 2015 are now resorting to organ sales (Cousins, 2016; Forum for Protection of People's Rights Nepal, 2016). One study of 100 kidney donors in Iran indicates that in 43% of the cases, the motivation to donate was financial, and an additional 40% said that it was mainly financial, with a minor altruistic component (Zargooshi, 2001a). Financial need was the motivating factor in cases of commercial donation globally.

**Lack of resources.** Globally, a lack of formal education and illiteracy, as well as inability to access public resources, are common themes among those who have their kidneys removed for compensation (Budiani-Saberi et al., 2014; COFS, 2011; Moazam et al., 2009; Moniruzzaman, 2012; Yea, 2015; Zargooshi, 2001b). The lack of resources likely contributes to the desperation that was experienced by individuals and then contributes to the decision to sell. The lack of education of the process of transplant and potential consequences also contributes. Hopeful that the sale will represent a positive shift in their family economic situation, vulnerable individuals become trafficked persons. Current literature indicates, however, that in most cases, they fair far worse post-transplant, meaning that they are more financially strained after the transplant, as compared to before (Budiani-Saberi et al., 2014).



**Poverty and decision making.** Studies in behavioral economics have explored the link between poverty and behavior (Banarjee, 2000; Bertrand, Mullainathan, & Shafir, 2004; Spears, 2011). Most relevant to organ trafficking is the discussion of how poverty impacts economic decision-making. Spears (2011) linked poverty to diminished behavioral control, claiming that poverty not only makes economic decision-making more difficult, but also changes the consequences of the decision. Study methodology included an experiment conducted in India where individuals were assigned to "wealth" and "poverty" groups and asked to participate in a "store game" that required decision-making based on their assigned category. The behavioral control of the study participant was determined based on their decision-making within the controlled study setting. Choices to purchase store items that represented investment, as opposed to temptation, were examined. The overall finding of that study is that when individuals were poorer, they face tempting economic decisions with reduced behavioral control and this impacted decision making (Spears, 2011).

Banarjee (2000) explains that there are two ways in which poverty can be viewed and that anti-poverty policy in general is impacted by these perspectives. Perceptions in economic poverty research have shifted from a traditional view that the "poor were much like anyone else," to one that encourages exploration of how poverty impacts action (Banarjee, 2000, p.129). Banarjee included two main points that are relevant to this study: poverty may change behaviors by making the individual desperate, and that poverty is a vulnerability. The described vulnerability relates to the ability of individuals to make economic decisions in the face of poverty. For example, individuals may make decisions that they otherwise would not, as a result of their economic situation. This is

particularly relevant to TPRO as vulnerability is examined for its impact on choice and free decision making. While behavioral economics have not been utilized to examine TPRO or the decision-making process to remove an organ and cited in the literature, the concepts are relevant to the exploration of decision making within this context.

Existing literature examines the impact of constrained economic decision making with regard to its application to anti-poverty policy, for example banking and saving decision-making. While the conceptual framework employed in this study is not consistent with current behavioral economics modeling, the implications of studies that examine decision-making can be useful when examining TPRO. The obvious difference in the conceptualization is the emphasis on vulnerability and how the abuse of vulnerability impacts decision-making, as opposed to diminished behavioral control (Gallagher & McAdam, 2013; Spears, 2011).

### **Post-transplant Consequences**

The decrease in individuals' quality of life post-transplant is widely discussed in the literature (Tong, Chapman, Wong, Cross, Batabyal, & Craig, 2012). Studies conducted in Bangladesh (Moniruzzaman, 2012), Egypt (Budiani, 2006; Budiani & Shibley, 2006; COFS, 2011), India (Budiani-Saberi et al., 2014; Cohen, 1999; Goyal et al., 2002), Pakistan (Moazam et al., 2009; Naqvi et al., 2008; Yousaf & Purkayastha, 2015), Iran (Nejatisafa et al., 2008; Zargooshi, 2001a/b), and in the Philippines (Awaya, 2009; Mendoza, 2010) indicate that individuals were in worse conditions financially and physically post-transplant. Noted among the negative consequences are familial and community shaming, isolation, loss of income, inability to resolve previous debts, physical pain, and weakness. A review of the literature also suggests that many donors do

not receive adequate follow-up medical care and this may contribute to the physical consequences of donation (Awaya, 2009; Budiani-Saberi et al., 2014; Budiani-Saberi & Mostafa, 2011; Zargooshi, 2001b). Compensation for donation does not appear to be adequate, as many have remained in debt post-transplant or experienced worsened financial situations as a result of the transplant and its implications for ability to work (Budiani-Saberi et al., 2014; Goyal et al., 2002; Yousaf & Purkayastha, 2015).

Even in Iran, the only country in which financial compensation for living unrelated donation is a legal transaction, commercial donors suffered consequences and expressed regret with their decision to sell a kidney. In Iran, because of the negative consequences post-donation, the majority of donors interviewed as part of a study agreed that commercial donation should be banned and, given the decision to make over again, would have preferred to beg for money or obtain a loan instead of selling a kidney (Zargooshi, 2001a). An additional study of 424 living unrelated kidney donors in Iran concluded that the quality of life is likely low among the population and that commercial donation may be associated with an increase in the risk of experiencing stressful life events (Nejatisafa et al., 2008).

### **Understanding the practice in India**

To fully understand the extent to which TPRO has been previously studied in India, a review of literature was conducted. Three studies have been conducted on commercial living donation in India. Data were captured through qualitative interviewing and ethnographic field methods and quantitative survey data. These studies provide a context for understanding how the practice operates in certain communities in India.

Cohen (1999) chronicled the experiences of trafficked persons from Chennai, a

city in the state of Tamil Nadu, which saw the collapse of industry and subsequent loss of income for members of the community. Specific methodological information is not provided in the text; however, Cohen (1999) provides a narrative for the examination of the experiences of a trafficked person. These include the physical and emotional pain that remains as a consequence of donation, as symbolized by the transplant scar. Cohen (1999) explores the reason for sale, and debt is cited as the main motivation for selling, noting the position of desperation and lack of choice due to both individual and community economic circumstances. For example, one individual interviewed indicated that “*running out of credit*” led to the economic situation that then led to his organ removal. Cohen (1999) concludes with a discussion of the ethics of commercial donation in India and a call for more data on the consequences. In particular, he examines the role of deceased donation in India as a way to curb commercial organ donation. He discusses the limitations to this model, a lack of infrastructure and a “*mentality that will not support it*” within the context of increasing commercial living donations, meaning the cultural understanding and acceptability of deceased donation

In 2002, a study was published that examined the economic and health consequences of commercial living donation in India (Goyal, Mehta, Schneiderman, & Sehgal, 2002). This was a mixed-method, cross-sectional study conducted in Chennai with 305 study participants. Qualitative interviews were conducted with study participants and participants completed a survey requesting information about family income and demographic information. The average age of the study participants was 35 years and females comprised 71% of the study sample. The purpose of the study was to examine the motivation for kidney sale and the physical, social, and economic

consequences post-transplant.

Findings from Goyal et al., (2002) built upon the work previously done by Cohen (1999), as the authors noted that debt was the main reason for donation and that those in the study sample suffered a host of consequences as a result of donation. Results indicate that 96 percent of study participants sold their kidneys to pay off debts (Goyal et al., 2002). Following the transplant, about 68 percent of study participants reported a decline in physical health status. Contributing further to the knowledge base, the authors also examined the compensation received by donors and the decline in average family income post-transplant. Data suggest that three-fourths of the study population were still in debt at the time of study participation (Goyal et al., 2002). The study concluded that commercial living donation in Chennai is associated with a decline in physical health and economic status. The strength of this study over Cohen's (1999) study was the inclusion of quantitative methods to examine the issue and an increased sample size to provide the power for quantitative analysis. The authors used change in family income post-transplant as a measure of economic consequence of commercial donation. This measure was critical in examining the association between commercial donation and economic benefit.

Expanding upon the previous studies conducted in Chennai, a study conducted between 2010 and 2012 collected data from 153 individuals drawn from four sites in India: Chennai, Erode, Karnataka, and West Bengal (Budiani-Saberi, et al., 2014). The purpose of the study was to examine the reasons for resorting to a kidney sale, the physical, social, and economic consequences post-transplant, and the process by which individuals became persons trafficked for their organ. Information on individual

knowledge of the recipient and payment were also collected. Semi-structured, in-depth qualitative interviews were conducted with study participants and demographic information was collected.

Results of the study found that in field observations, study participants were living in extreme poverty. Qualitative data suggested that debt was the primary reason for sale (87.7%), while others cited the desire to have a new opportunity and coercion as the main reason for sale (COFS, 2014). Debt was further examined and study participants indicated that debt was caused by loss of income, marriages, family illness, familial substance abuse, children's education, or by being abandoned or widowed (Budiani-Saberi et al., 2014). Study participants suffered a variety of consequences that included physical pain and inability to work, fatigue, anxiety, guilt, depression, and fear of death because of the organ removal (Budiani-Saberi et al., 2014).

The study conducted by Budiani-Saberi and colleagues (2014) contributed to the understanding of the reason for sale and the consequences of commercial donation, but also increased understanding of the process of commercial living donation for the individuals in the study sample. The expansion of the study to four sites in India enabled researchers to examine findings from each region and to develop research questions to conduct additional in-depth follow-up studies. Data that were collected in West Bengal, a state in the eastern part of India with the capital city of Kolkata, is of particular interest as it represents the only data that have been formally collected in that state. The findings suggest that differentiation exists in commercial donation in West Bengal compared to Chennai and other parts of Tamil Nadu. One important finding is that the gender makeup differed among the sites, with a higher number of female PTORs in Chennai, as

compared to other sites in India. However, the higher percentage of male vs. female PTORs mirrors the demographics in other countries (Awaya et al., 2009; Moazam, Zaman & Jafarey, 2009). The transplant was not always conducted in the state of the residence of the study participant, but of the 30 individuals interviewed from West Bengal, 26 transplants occurred in Kolkata (COFS, 2014). The individuals interviewed in West Bengal did not have access to any form of public service and did not have paved roads, electricity, or access to healthcare or transportation, possibly due to their physical location and poverty, compared to those living in urban environments in Tamil Nadu. Findings from this study indicate that the study population was malnourished and that a lack of food due to a lack of money was a motivating factor in the decision to sell a kidney; in contrast, individuals in Chennai and Erode were motivated more by the loss of income and industry (COFS, 2014).

Beyond the studies in peer-reviewed literature that have been conducted, journalists also report on commercial living donation in India (Gowhar & Yasmeen, 2013; Kannan, 2014; Robinson, 2008; Schmitt, 2007). For example, Gowhar and Yasmeen (2013) conducted an interview with a broker and explained how recipients connect with donors and the article provided some anecdotal information on how this process works in a particular community in India. While information reported from international and Indian national media sources cannot be verified and data were not collected using appropriate research methods, it is worth noting its existence and considering the contributions that journalists have made in understanding the issue of commercial living donation in India.

## **Gaps in Literature**

Various studies exist that have created a foundational understanding of how poverty is linked to commercial donation globally and how individual donors experience physical, economic, and social consequences as a result. Specifically in India, Cohen (1999) explored the economic origin of organ sales and linked poverty to organ removal in one community in Chennai. Expanding upon this study, Goyal and colleagues (2002) further delineated the connection between debt and kidney removal, and described in greater detail the physical consequences post-transplant. While this study contributed to knowledge of the phenomenon in Chennai and supported past research (Cohen, 1999), it did not increase knowledge of the practice outside of one specific community. Additional studies conducted outside of Chennai were useful in filling important gaps in literature by expanding to multiple sites in India (Budiani-Saberi et al., 2014). Budiani-Saberi and colleagues studied the phenomenon in four sites, both in southern and northern India. Their study also explored motivating factors and consequences as previously studied, but expanded to include an exploration of regional and gender-related differences. Missing in the literature is an exploration of what specifically makes individuals vulnerable to organ sales. What poverty characteristics impact organ sale status? How are other impoverished individuals protected from organ sales? It is important to not only understand that poverty is linked to organ sales, as established empirically, but to understand the mechanism by which this occurs and the related characteristics or factors. This proposed study serves to fill this gap in knowledge for one specific community and one context.



## Chapter 3. Methodology

### Introduction to Design and Methodology

The purpose of this study was to understand how individuals in the study sample from a specific community in a Northern state in India became persons trafficked for organ removal (PTOR), particularly how risk factors contributed to vulnerability and the occurrence of a kidney sale. A related purpose was to explore the protective factors of individuals who were aware of an opportunity to receive payment for an organ, but did not have an organ removed. Within this specific context, the circumstances or factors that contribute to the individual's vulnerability to kidney sales were explored. The definitions of specific terms, as they are being used for the purpose of this research study, are shown below in Table 1.

Table 1. Study Concepts

Term	Operational definition
Trafficking in persons	Trafficking in persons shall mean the recruitment, transportation, transfer, harbouring or receipt of persons, by means of the threat or use of force or other forms of coercion, of abduction, of fraud, of deception, of the abuse of power or of a position of vulnerability or of the giving or receiving of payments or benefits to achieve the consent of a person having control over another person, for the purpose of exploitation. Exploitation shall include, at a minimum, the exploitation of the

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	prostitution of others or other forms of sexual exploitation, forced labour or services, slavery or practices similar to slavery, servitude or the removal of organs. (United Nations Office on Drugs and Crime, 2015, p. 14)
Person trafficked for organ removal (PTOR)	An individual who received or was promised material gain for their kidney. This individual may have learned of the opportunity to sell their organ from an organ broker, family member, community member, or other form of media including a newspaper or internet advertisement.
Not a person trafficked for organ removal (NPTOR)	An individual who was aware of the opportunity to receive material gain for a kidney removal through various sources, but did not have it removed. The source of the information may have been organ brokers, family members, community members, or other form of media including newspaper or internet advertisement.
Vulnerability	Individual or community susceptibility to harm or disaster due to some combination of social, economic, physical, or environmental factors.
Risk factor	Specific factors that increase vulnerability to disaster that might include: lack of resources, gender, location of residence, poverty, political

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	infrastructure, race and ethnicity, hunger, or
	community violence.
Protective factor	Specific factors that reduce vulnerability to
	disaster that might include: donor assessment
	process, family, social networks, education, self-
	determination, or opportunity.

### Research Design

To understand influences that both make individuals susceptible to, or protect them from being trafficked for the removal of kidneys, the following study research questions were used:

- What are the life circumstances or factors that make individuals vulnerable to being recruited to sell an organ?
- What factors protect individuals from having an organ removed for compensation?
- Does the living donor assessment process serve as a mechanism to protect individuals from kidney sales?

To address these research questions, a qualitative study was conducted using a non-experimental design. This specific research design and method was chosen because qualitative data are needed to answer the proposed research questions. Qualitative methodologies, primarily ethnography and intensive interviewing, have been utilized to understand the experiences of PTORs (Budiani-Saberi et al, 2014; COFS, 2014; COFS, 2011). This research study was conducted using intensive interviewing and guided by a constructivist grounded theory (CGT) methodology (Charmaz, 2014; Charmaz, 2006).

Due to the nature of inquiry, grounded theory methods were employed to allow for systematic, yet flexible, data collection with the purpose of constructing theories that are grounded in data. Grounded theory methods were appropriate for this study because the aim was to develop theory to explain how vulnerability is linked to trafficking in persons for the removal of organs (TPRO) in this context. Instead of developing hypotheses and using deductive reasoning, inductive reasoning was used to firmly ground the theory in a deep understanding of the issue. Intensive interviewing was employed as the method for collecting data from study participants.

Grounded theory gained attention in the mid 1960's with the introduction of the method by Glaser and Strauss (1967), researchers who sought to provide a method by which qualitative researchers could further control the research process, increase rigor, and increase the analytic power of their research. This method is characterized by a systematic effort to develop theory from the data using a variety of analytic techniques, a dramatic shift from the customary research practice of deducing testable hypotheses from existing theories (Glaser & Strauss, 1967). Grounded theory methods guide the researcher through an iterative process that requires the researcher to constantly compare and analyze the data, even during the data collection process, in an effort to define concepts that fit the data and to advance the theory development at each stage of data collection and analysis. Grounded theory has undergone transformation in the last four decades as researchers have challenged and fine-tuned the defining points of the method in an effort to increase rigor, reflexivity of the researcher, and to recognize the role of researcher in constructing the theories that emerge from the data (Charmaz, 2006).

This study incorporates elements of traditional grounded theory (inductive

process of data collection and analysis, theoretical sampling), through a constructivist lens (Charmaz, 2006). A constructivist grounded theory (CGT) approach fuses traditional grounded theory practices with reflective practices. Charmaz (2006) notes that CGT requires more emphasis on processes and understanding of the role of the researcher in interpreting findings. This method allows for more flexible guidelines for data collection and analysis, as opposed to rigid methodological rules or requirements. The flexibility is inherent in a CGT approach because constructivist researchers recognize that the researcher is a player in the world that is being examined.

From this perspective, grounded theories that emerge from the data remain a construction of the reality that was observed by the researcher through interactions with research participants with varying perspectives, research practices, and the researcher's own individual lens (Charmaz, 2006). CGT accounts for the co-construction of theories incorporating the perspective and reality of study participants and the researcher, giving weight to how these perspectives influence the analysis of data and development of theory. Examining the data through a constructivist lens is particularly useful for this study due to my previous experience with the study population. Personal biases and assumptions about the factors that contribute to kidney sales in the specific community may ultimately impact the study results. Past work and advocacy experience with organ donation influence my understanding of how donors consent to organ removal and my perspective on the role of coercion, exploitation, and victimization. This understanding is a product of experiences, but also of worldview, and related to my position of power and privilege. The iterative process not only allows for constant comparison of the data to achieve theoretical understanding, but also serves as a mechanism for checking and

recording how and when my interpretation of reality surfaced during the process, with special attention to when my interpretations were in conflict with my research respondents' assertions. The constructivist lens was chosen to reduce the effect of personal biases on the theories that emerged from the study, biases that are constructed according to personal reality (previous experiences, notions). Proactive strategies were developed to reduce bias with outright recognition of how biases may guide and impact data analysis. Biases were identified and a protocol for the study was developed. The study protocol was reviewed and approved by the Rutgers University Institutional Review Board (IRB). I was also formally affiliated with the Centre for Studies of Social Sciences, Calcutta and received general research mentorship.

### **Ethics**

A specific informed consent process was employed, as approved by the Rutgers University Institutional Review Board, to ensure that data were collected in an ethically appropriate way. The consent process is described in further detail in Chapter 8. The research protocol was approved before the study began and subsequent amendments were also approved throughout the data collection process. Additional amendments included the inclusion of a second language for conducting interviews and the expansion of inclusion criteria.

As the aim was to interview individuals from vulnerable populations, it was critical to develop a process by which individuals could choose to participate in the research study with a full understanding of the potential risks and benefits. The potential risks that were explained to participants included emotional risks, as the interview related to a difficult time in their life, and community or family risks with the potential for

others to judge their participation or their status as a PTOR. It was explained that there were no foreseeable physical or legal risks, as no medical testing would be done, and that information would not be shared with any legal officials or law enforcement. Economic risks were not present because interviews were scheduled at a time that would not interfere with livelihood activities. The research team also described the potential for the loss of confidentiality and the steps that were taken to ensure confidentiality of information and status. The interview allowed participants to share their experiences and also to contribute to a knowledge base that may lead to the development of programs or policies to help others who have been trafficked or are vulnerable to trafficking.

All participants were able to ask questions prior to the interview and discuss any concerns. Due to the criminalized and highly stigmatized nature of trafficking, participants may have been fearful of signing a document, therefore, a waiver of written consent was requested and granted. Participants were able to give oral consent to participate in the study and a signature or thumb print was not required. All individuals were required to give their oral consent. A requirement for participation was that participants had to agree to the audio recording of the interview.

Throughout the study, from initial study conception to data collection, a partnership with a local community organization was sustained. This organization is mentioned multiple times, but is not named. The primary reason for not naming the organization is to maintain the confidentiality of the research participants. The community in which data collection took place is small and there are only a handful of organizations that serve residents. If the name of the organization was provided in this dissertation, it would be immediately evident to those who are familiar with the region

that the study participants reside in a specific community.

As most study participants were recruited by a field researcher who worked for a local community organization and was acquainted with the individuals and their status (PTOR or NPTOR), it was particularly important to consider the role of pressure and undue influence. In addition to all of the critical components of the consent process, we conscientiously worked to explain that if they chose to participate, it would not impact their relationship with the community organization at all. The consent process was critical in ensuring that the research participants were aware of purpose of the research and had realistic expectations about the potential benefits of the study.

Explaining the risks and benefits was an ongoing process throughout data collection. Despite having thoroughly explained the potential benefits prior to the interview, many individuals requested additional assistance following the interview and inquired about what specifically they could receive in the future. This was a challenging part of the data collection process, but diligence was required to confirm that participants were fully aware of the potential risks and benefits.

No incentives were provided for participation in the study. This decision was made after careful thought and consideration as to the role that incentives might play in recruiting participants. Due to the socio-economic status of research participants, incentives were not provided because of the risk that participants would only agree to be in the study because the incentive was needed. It was critical for individuals to choose to participate of their own free will and with complete understanding of the study.

Ensuring safety of the research participants required continued effort. I worked to provide a safe environment and had a familiar person (field researcher) first approach



potential participants. It was not unusual for the field researcher to communicate with a potential participant, as it was common for the field researcher to interact with many of the community members. As described in more detail below, the time and place of interviews were also chosen to provide a safe environment.

In order to ensure the safety the research team, all possible dangers were considered. While not all potential dangers were known, conversations with field partners and local residents were helpful in developing a plan to address them as best as possible. Some of the activities to ensure safety including periodic “check-ins” with my dissertation chair and family members in the United States. The University of Texas at Austin (2010) developed guidelines to ensure field researcher safety. The guidelines recommend assembling safety gear that will be needed to protect against environmental hazards while in the field. The items that I always utilized were sunscreen, insect repellent, and a bed net. The Centers for Disease Control and Prevention recommendations for travel in India were considered which included receiving necessary vaccinations and avoidance of behaviors that may impact physical health while in the country (CDC, 2017). Options were limited in rural areas and it was necessary to eat foods that were prepared differently than desired. In these instances, it was important to consider the amount of food consumed, while remaining respectful and culturally appropriate.

### **Sample**

There were two distinct target populations from which the study population was derived: trafficked persons and non-trafficked persons living in a specific community in Northern India. In addition, two community leaders were interviewed. The experiences of

the two leaders were critical to understanding the community as a whole, particularly to understand what economic and social opportunities exist, either through government programs or the local organization. All participants were chosen based on specific pre-determined inclusion and exclusion criteria. Individuals from both samples must have had the ability to give consent to participate in the study.

For the sample of persons trafficked for an organ removal (PTOR), study participants were all individuals who had had a kidney removed, who either received payment, or were promised payment for a kidney, were age 18 or older at the time of organ removal, and were living in the specific district during the time of organ removal, although some may have been on temporary assignment there from out of state. The organ removal must have occurred within the last ten years. Pregnant women were not intentionally excluded from participation, but there were no pregnant women within the sample.

For the sample, those who were not trafficked for an organ removal (NPTOR), study participants were individuals who were aware of the opportunity to receive compensation for an organ, but did not have an organ removed, age 18 or above, and who lived in the district when becoming aware of kidney sales from a community member or family member or through a specific instance where the individual was recruited or targeted for kidney sale from an organ broker or healthcare professional. No pregnant women were included in this study group.

The study sample included 23 PTORs and 20 NPTORs. All demographic characteristics of the study participants are reported in Chapter 4, in Table 2.

Sampling within grounded theory should be aimed at the construction of theory,

rather than to achieve population representativeness (Glaser & Strauss, 1967). Purposive sampling was used to obtain study participants. Cooperation with field partners (local community group, international group based in India) was critical in identifying potential study participants. A community partner initially contacted potential participants and those who were interested received study information prior to giving oral consent for participation.

### **Interview Guides**

The process of developing interview guides began with a list of sensitizing concepts (Blumer, 1954; Charmaz, 2014; Charmaz, 2006) and general perspectives about the research questions. The use of sensitizing concepts is common in constructivist grounded theory research, as the concepts provide a theoretical foundation and starting point for developing theory (Bowen, 2006; Charmaz, 2014, Charmaz, 2006). The sensitizing concepts were developed based on a literature review and were initially used as background ideas that guided the study. The list of concepts was useful in initial data collection and in providing a loose guiding framework. Specific hypotheses were not developed, as grounded theory is a method where data are used to further understand and develop theory, nevertheless, personal knowledge and experience did guide the development of these sensitizing concepts, as well as the creation of the guides. After the list of sensitizing concepts was compiled, the data collection sheets and interview guides were developed.

A data collection sheet was developed for trafficked and non-trafficked persons that included demographic questions. The data collection sheets included general demographic questions and included questions that were specific to donors' organ

removal, including year of transplant and place of organ removal. Two interview guides were developed initially, one for trafficked persons (PTOR) and one for non-trafficked persons (NPTOR). The PTOR interview guide contained 25 questions and was organized according to five broad sensitizing concepts (vulnerability and motivation, recruitment and targeting, deception and coercion, donor assessment process, and post-transplant consequences). The NPTOR interview guide was comprised of 19 general questions, with four sensitizing concepts that were distinct, yet connected, to the concepts in the donor interview guide. The four sensitizing concepts included were family and social support, opportunities, knowledge, and the decision-making process.

The data collection sheets and interview guides were developed in English and then were translated in to two languages (one common and one tribal). The translation of the documents in to Bangla was completed initially by a language consultant and then read/discussed for accuracy by two research assistants who were fluent in speaking both languages. The translated documents were typed in Bangla. The Santali language was introduced mid-way through the study and the documents were translated by a research assistant and then read for accuracy by the other field researcher who was also fluent in the language. Due to the inability to type Santali, because of the lack of software, the documents were hand-written. When translating the study documents, there was a risk of translation non-equivalence and the literature indicated that other issues may arise in cross-cultural translating which may include issues with vocabulary, idiomatic, or experiential equivalence (Cha, Kim, & Erlen, 2007).

The advice and expertise of field partners and subject matter experts was sought to ensure that the guides included questions that would help to answer research questions

in a culturally appropriate way. Models of group discussion (Brislin, 1970; Cha et al., 2007; Jones et al., 2001) were utilized to achieve cultural translation of the documents. Understanding that donors in the sample would likely have little formal education and may be illiterate (Budiani-Saberi et al., 2014), questions were developed with this fact in mind and I was cognizant of terminology, avoiding concepts that are not translatable across languages. The interview guides were developed with the understanding that not all concepts will translate and some may require either a re-examination of the concept or a change in the operational definition (Jones, Lee, Phillips, Zhang, & Jaceldo, 2001). The interview guides were pilot-tested in the community. Following pilot-testing and meeting with subject matter experts and field partners, they were utilized in the study.

Despite having pilot-tested the interview guides before beginning the study, some of the questions were deemed culturally inappropriate or irrelevant during the data collection process and were removed. For example, the initial interview guides for non-donors included a section on family and social support. Within this section was a question, *How would you describe how your family is organized?* This question in particular did not require editing or removal during the pilot-testing phase, but was later removed when new understanding was gained about the patriarchal nature of families within the community. The question was inappropriate given the research setting and participants had difficulty understanding the concept and answering the question. The original donor interview guide contained the sensitizing concept of deception and coercion. This was included due to current literature and personal understanding of the elements of deception and coercion as factors in kidney sales; however throughout the process, it became apparent that there was initially too much focus on this element. The

concept of coercion was not understandable within the context, particularly because the trafficked persons study participants did not generally view themselves as victims of coercion.

As data collection continued, the content of the interview guides changed. New questions and sensitizing concepts were explored throughout data collection. It is appropriate and necessary in grounded theory methodology to engage in an iterative process by which data collection and analysis occur simultaneously. As new concepts and themes began to emerge within the data, the interview guides were edited to reflect these changes. Throughout the process, questions were added and removed on a regular basis. The strategy for updating the interview guides included initial interviews of between 3 to 5 individuals, transcription and translation, and then analysis to determine the existing need for changes within the interview guide. The component of constant comparison and the flexibility within the method allowed for the inclusion of new sensitizing concepts not originally considered. The final data collection sheets and interview guides are available as follows: trafficked persons (Appendices A and B), and non-trafficked persons (Appendices C and D).

### **Data Collection**

Two individuals with the appropriate educational background, language, and skill sets were chosen as field researchers for the study. The main task of the field researchers was to assist in participant recruitment and facilitate data collection interpretation. Field researchers did not analyze data. Both individuals were native Bangla and Santali language speakers and had extensive previous experience with the specific community where the research participants resided. A comprehensive training was conducted to

ensure that field researchers were conducting study related activities according to ethical guidelines. The training included components on ethical interaction, safety, and data integrity. The researchers also completed the necessary ethical training as required by the Rutgers University Institutional Review Board.

All interviews were conducted in-person by the researcher with the assistance of field researchers. The interviews were conducted in either Bangla or Santali, depending on the native language and preference of the research participant. The interviews were conducted at accessible and secure locations, some interviews were conducted at the participant's home and others were conducted at a private center within the community. Interviews lasted from 35-70 minutes. Interviews varied in length due to environmental, family, and community factors including heavy rain and mud, participant family emergencies, unanticipated lack of privacy, or the need to tend to livestock or land. It is also important to note that the subject matter of the interviews was extremely confidential and interviews were stopped according to the comfort level of the participant and if there was a potential breach in confidentiality. For example, it was not uncommon for a neighbor to come to the home of study participant unannounced during the interview. As the homes in the community are in close proximity to one another, it was important to be cognizant of the potential for others to be listening to the interview. Interruptions of daily life occurred that required some participants to be interviewed more than once to gather all necessary data. Follow-up interviews were conducted with some individuals who were unable to share more information during the initial interview. Most interviews were conducted in the morning between 7:00am and 9:00am so as to not interfere with the work and livelihood activities of the research participants.

The field researchers were hired to aid in the identification of study participants, help facilitate the oral consent process, and assist in data collection and analysis. Individuals who had been identified as potential study participants were contacted and asked if they were interested in learning more about the study. Most potential participants were familiar with one of the field researchers and had previously engaged with her on issues related to community issues or organ sales. One of the field researchers was well known to the community and had been active in various efforts to help community members through her role at a local organization for many years, and therefore the study participants had a favorable opinion of the researcher. The other field researcher was new to the community, but was respected due to her affiliation with a local faith-based community. Recruitment procedures included an initial home visit or phone call by a field researcher to gauge interest. It was not uncommon for individuals to not be interested in participating or being contacted by the research team. In these instances, the individual was not further approached or contacted for participation in the study. Those who were interested were met by the research team and given more information about the study. After gaining the participant's oral informed consent (i.e. waiver of documentation of informed consent) for the interview and permission to digitally record it for the study, the interview began.

During the interviews, the research team used the guides to complete the interview. The data collection documents were written in English, and translated into Bangla and Santali. One data collection sheet and one interview guide was printed or handwritten and used during the interviews. Electricity was not stable and there was often no access to a printer during many stages of this research phase, so handwriting was



essential. All interviews were audio-recorded, no information about the participant was written down. Only participants who granted permission to be audio recorded were able to participate in the study. Following data collection through an audio-recording device, the data were typed. All notes that were collected through the memo-writing process were handwritten.

Transcriptions and translations were done in a systematic way. The name of the participant, while on the audio recording, was not included in the transcription and translation document. This identifiable information was recorded on a separate electronic document that included the date, time, and other pertinent information. The responses of study participants were linked to a unique ID. The electronic document that was maintained provided a key that linked the ID to a specific individual. This document was critical when follow-up interviews with some study participants were required. The translation and transcription of the data were done in a private setting to ensure the confidentiality of the study participants. Once the interviews were translated into English, any information that would identify the participant, their community, or another individual was removed. For example, many participants spoke of the broker who connected them to the recipient by name and all trace of this individual's name was removed to maintain the confidentiality of the participants. The audio recordings were translated personally with the help of the research assistant in a joint effort to ensure understanding of the data.

The translation of the data was conducted by an individual who has his/her own lens which impacted the way that the data was translated. While the interpreter was fluent in all relevant languages, some concepts do not directly translate across languages. In

these instances, it was the role of the interpreter to determine the best way to explain the concept in the other language.

Continual transcription and translation were required to compare the data from interviews in order to code and to develop the conceptual understanding and to ensure methodological rigor. To engage in this process, 3 to 5 interviews were conducted and then transcribed and translated from Bangla or Santali to English. Generally the research team would conduct 3 interviews, then transcribe and translate those specific interviews to allow for changes to the interview guide depending on patterns that emerged in the data. This ongoing process of data collection, followed directly by translation and analysis, continued for all interviews. A total of 43 individuals were interviewed for this study (23 PTORs persons and 20 NPTORs).

### **Data Analysis**

Data collection and data analysis occur simultaneously under a constructivist grounded theory (CGT) approach. Kathy Charmaz' (2006) model for CGT and model was utilized for dissertation data collection and analysis. CGT is a process of using continual and iterative data collection and self-reflection techniques to develop a theoretical understanding that is grounded in the data.

Data collection using CGT requires specific levels of coding the data with the purpose of coding to understand the data collected and to guide the subsequent data collection to follow. The first level of coding, initial coding was used to answer broad questions, specifically what are the data saying? Once three to five interviews were completed, initial coding began. Initial coding entailed specific line-by-line coding that described a specific quote or piece of data. This technique included breaking up all of the

data into segments and then assigning a code or label to each segment. As suggested by Charmaz (2006), the data were initially coded using short action sentences to capture the full meaning of the quote, as opposed to a general concept. During this coding phase, data from the donors and non-donors was kept separate and I aimed to find meaning within each group. All of the coding that was done in field was done manually and without the assistance of the research team. Once I returned to the United States, all data were uploaded to my password protected computer for analysis with Atlas.ti. I used the written coding that had been done in India to code and manage data to enhance my analysis. Coding was helpful in identifying the similarities and differences among PTORs and NPTORs in an effort to understand individual and collective vulnerabilities and protective features. The method also helped identify assumptions and gaps in the data which allowed for changes to the interview guide according to the themes that were emerging. For example, understanding of prior research had led to inquiring about acute time pressures in the individual trafficked person's life that may have contributed to their vulnerability, such as an ailing family member who required timely surgical intervention. During the data collection process, it emerged that not only were pressures being experienced from within the home, but that there were external pressures, i.e. the failing health of the potential recipient, which also influenced vulnerability. Outside pressures were not previously considered until the topic emerged in the interviews. This may have been due to my previous assumption that altruism or concern for the potential organ recipient was not a factor, which was incorrect in some instances.

Following initial coding, focused coding was employed. All of the initial codes were examined and were collapsed conceptually. Throughout the initial coding process,

on numerous occasions, initial codes were assigned that were similar to other existing initial codes. The purpose of focused coding was to determine where and how codes could be combined and linked for more direct conceptual coding. Instead of individual coding line-by-line, focused coding allows for comparing the existing codes and allowing the data to illuminate categories of codes (Charmaz, 2006). At this point, the codes that were separated for PTOR and NPTOR were being compared. The purpose of this phase of coding was to determine what larger patterns exist, not only within the population-specific data, but also across groups to determine the similarities and differences between the data from those who were trafficked for organ removal and those who were not.

After the series of focused codes that emerged from the data had been created, theoretical coding analysis helped to determine how these codes relate to each other. This is the stage in coding where themes within the data were determined, for example, the role of family varied depending on the population, and how they related to each other. Connections were drawn among concepts to enhance my larger theoretical and analytic understanding of the vulnerability and protective factors each group exhibited. The purpose of this coding process is to understand and weave concepts together to develop a theory that explains the data and answers one's specific research questions (Charmaz, 2006).

Once concepts began to emerge within the data, there was a degree of theoretical sampling where individuals were asked to participate in a follow-up interview (note, this second interview was approved as part of the protocol and part of the informed consent process). The need for theoretical sampling became apparent following the initial and focused coding, as well as through the memo-writing process. Throughout the data

collection and analysis process there were specific themes that emerged from the interviews and the theoretical sampling was used to hone in on these specific concepts and gather more information. One theme that emerged within the data was the individual's ability to change his or her mind and to make a different decision. After multiple PTORs expressed that they had no ability to change their mind, it was important to return to participants to gather more information. This became an interesting theme, as most PTORs did not feel that they were tricked or deceived, but conversely described their inability to change their mind before the transplant occurred. This is one example of the complex and often contradictory themes that arose in this study which required theoretical sampling to understand.

Memo-writing is a technique used throughout the data collection and analysis process (Charmaz, 2006). It is a tool for accumulating concepts and relating these concepts to one another, as well as a way to creatively process data to reach higher conceptual understandings. Memo-writing is a form of writing where the researcher jots down thoughts about how they understand concepts within the data or document their thoughts as they compare concepts within the data. Generic prompt questions that are available in Kathy Charmaz' (2006) text were helpful in writing initial memos. These prompt questions encouraged thinking and free-writing techniques. Some examples of prompt questions that were used are *What are people saying?* and *What connections can you make?* (Charmaz, 2006). Following every three to five interviews, I wrote a memo capture my initial thoughts and questions. These memos were used to alter the interview guides and to focus the subsequent interviews with an aim of expanding upon my thoughts or answering my questions. For example, I used memos to explore how the

family serves as both a protective and vulnerability factor at the same time and for both groups of participants. Family support was initially not included in the interview guide for PTORs beyond whether or not their family member had also been trafficked.

Through this memo-writing process, the need to explore how family opinion, structure, and support were factors for both groups of participants was discovered. The memos were also helpful in documenting how my personal perceptions were potentially impacting the data analysis.

Memos were critical in comparing my written understanding of the data with the actual data from the participants. Memo-writing serves as a tool within grounded theory that allowed me to stop and analyze my ideas beginning early on in the process and continuing throughout the study.

### **Trustworthiness**

In qualitative research, the rigor of the study is based on a number of specific measures. As reliability and validity speak to the quality of quantitative research, there are measures that establish comparative reliability and validity in qualitative research. These measures fall under four distinct criteria which include credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985; Shenton, 2004). This section will detail the measures used to ensure the accurate representation of the participants' experiences.

**Member checking.** Member checking is a strategy used to ensure that the data that has been recorded and the understanding of what has been gleaned by the researcher will match the experiences of the research participant. During data collection, a process of “on the spot” member checking was used. This form of member checking involved

periodically repeating the information that the research participant had shared during the interview in an attempt to ensure that the data were being understood correctly. Due to the constraints of the environment and the nature of the research, it was difficult to return to participants solely for member checking.

**Prolonged engagement.** The language training that I participated in allowed me to spend more time in the state in preparing for data collection and to immerse myself in the culture. While culture in the larger city in the state does vary from the rural culture of village in which I collected data, spending these 4 months in both language and cultural training added to my understanding of broad social issues, the factors that undoubtedly impact the occurrence of kidney sales. My time in the city also allowed for the exploration of the healthcare systems and the transplant hospitals, where many of the research participants had their organ removed.

In addition to the four months of language training, during data collection I spent five months living in the specific district of the Northern State where I spent the majority of this time living in the village. Over the course of the 9 months, I worked to truly experience and understand the lives of the individuals who were the research participants in an effort to most accurately capture their stories. While more time in field would have inevitably increased the rigor of the study and my personal understanding of the issue, financial and personal safety constraints did not allow for this.

**Background/qualifications of the researcher.** I have been working with the Coalition for Organ-Failure Solutions for five years to understand various elements of the experiences of individual PTORs. I have been engaged in understanding the issue internationally, but more specifically in India. I was involved in a research study to

understand how organ trafficking operates in four specific communities in India and subsequently have published in this area. In addition, I participated in the Doha Donation Accord in Qatar in 2014, an international summit that examined ethical issues related to organ trafficking and organ trade.

Prior to data collection, I completed two semesters of Bangla language instruction at Rutgers University. During the fall of 2014, I attended the American Institute of Indian Studies Bangla Language Program. This program was a four-month intensive language immersion program. In addition, I was immersed in the community, as I lived within the community of study during data collection.

### **Reflexivity statement**

Past and current experiences as a research intern at an international health and human rights organization focused on TPRO undoubtedly shaped my research questions and the development of both my proposal and the analysis of my data. In the early stages, opportunities to attend international meetings and speak with experts on the topic were possible because of my affiliation with the organization. The relationships that I have built have been directly due to these experiences and they framed the development of current and relevant research questions. I chose to study TPRO because of a personal interest and the apparent need for additional research in this field. These experiences impact how I view the role of personal decision-making, consent, and motivation with regard to organ trafficking and trade.

I hold a general value that individuals who have sold a kidney did so because of social, economic, and environmental conditions that made them susceptible to harm. While research indicates this is the case, this perspective means the role of self-efficacy



and choice may be diminished or lessened. Guided by international documents that frame the role of consent and human trafficking, I hold a belief that individuals who remove their organ for material gain are in fact exploited for their organ.

Reduction of personal influence on data analysis was a goal of mine, as complete elimination of bias is not possible. Through self-awareness and reflexive practices, I tried to become aware of how my assumptions were impacting the study.

I originally began this study with the desire to find answers that could be neatly packaged, that would yield recommendations or strategies to end the practice in the community. While I have succeeded in developing recommendations, I have realized that this issue is much more complex, and that the agency and self-determination of those trafficked for organ removal cannot be diminished or ignored.

## **Chapter 4. Findings- Economic Influences**

In this chapter, findings are presented that emerged from qualitative interviews with a total of 43 participants (23 Persons Trafficked for Organ Removal, 20 Not Persons Trafficked for Organ Removal) in a specific community. The purpose of this study was to delineate the differences between the two groups of participants and determine which protective and risk factors contribute to susceptibility to trafficking in persons for the removal of organs (TPRO). This grounded theory dissertation, as discussed in Chapter 3, required a flexible, iterative process of coding to produce findings that are rooted in the data. This chapter will focus specifically on the economic environment in which organ sales occur, and will explore distinct and sometimes intertwined economic and personal motivations for selling a kidney. To understand the findings within the specific community context, a description of the research setting is included. Demographic data were collected from both groups of participants, and the results are provided below in Table 2, with additional demographic characteristics described.

### **Research Setting**

The description of the research setting is written as descriptively as possible. Nevertheless, for the safety of the research participants, it is imperative that readers of this dissertation not be able to identify the community from which data were collected, therefore some specific details are not included in the description. The community in which this study was conducted is located in a Northern state in India. It is a cluster of villages that are within close proximity to each other; it is rural, agricultural and remote. It is an area of rich soil and ponds that are full of fish. The community has large, lush trees, bamboo groves, mango trees, maize fields, and wheat fields. Maize and paddy are

the most important crops; maize is a cash crop. All across the village roads, one could see maize pods being dried by being spread neatly on the road surface; these pods are then sold and the kernel used as fuel in rural households. Many crops are cultivated in this and in the surrounding communities, despite the extreme poverty of many in the community. Mango, lychee, coconut, jackfruit, papaya, and mustard also grow in this region. Depending on the season, the remnants of the seasonal fruit can be seen along the side of the road. For example, during mango season the pits can be seen on the ground of the local market and along the street paths.

It is also common to rear animals in this region of India, with many people owning or renting goats, chickens, and cows, depending on their income. Lots of goats can be seen munching on shrubs and grasses along the roadside. It is unusual to see pigs, but some residents rear pigs. Other animals such as dogs, cats, lizards, snakes, and birds are also present. Unlike in most large Indian cities, many of the dogs are not street dogs, but rather belong to families for added security and protection. However, they are not welcomed into the home as domesticated pets; they stay outside and are not petted by their owners.

The homes in this community are generally made of mud, clay, and sticks/leaves that are woven together. Some homes are made of concrete and the roofs are metal panels or tarps. Homes are very close to other another and families often share a path to their home, which limits privacy among neighbors, as conversations can be heard from one home to another. Most of the cooking is done outside of the home with a fire pit and large pots outside. The line to hang laundry often is nearby. All of the laundry is cleaned by hand and is hung on the line to dry. Inside the home, it is common to see a representation of their god or spiritual leader (in picture or statue form), a bed with an attached mosquito

net, books, and a paper wall calendar that is provided by a local organization. Only a few of the research participants that were interviewed own a television.

Women in the community wear lightweight cotton saris or long traditional shirts with matching loose fitting pants. Young girls wear Indian style dresses with leggings. Men wear large pieces of cloth that are wrapped around the body, or pants; young men wear jeans and Western shirts. It is very unusual to see women in Western clothes in this community. Women, men, and children wear sandals year-round and wear socks with sandals in the colder months. Babies generally wear small shirts, and because diapers are not used, some babies are nude on the bottom while others wear simple underpants. Jewelry is commonly worn by women and it is a mark of culture, religion, and status. Women often wear bangles (bracelets), necklaces, and earrings, and they have their noses pierced.

The main roads to the community are paved, but many roads within the community are made of dirt and rock. The terrain does not allow for just any type of vehicle to traverse, but requires a vehicle with large tires that can drive on the many unpaved roads. Roads are very narrow and often heavily potholed. The primary modes of transportation are shared vehicles (rickshaws), buses, motorcycles (referred to as scooties) and walking. Small vehicles with flat beds are also available for local transport, they cannot go long distances. It is extremely rare to see a private vehicle and the sight usually indicates that a government official such as a politician or local doctor is present, or that someone from outside of the community is visiting.

There is a local government doctor's office in the community, though it has limited capability. If a patient is suffering from a condition that requires specialized

treatment, requires a medicine that is not readily available or common, or surgery, the patient is sent to the larger government hospital. Government doctors' office and hospital services are free, but individuals must cope with long lines to be seen. There is no ambulance system in this community, causing residents to often die because they are not able to make it to the closest city for treatment. Some residents adhere to traditional and alternative medicines and seek the advice of local alternative medicine specialists in the villages.

A faith organization provides social services to residents, including a school that students can attend for a very low cost, and a pharmacy. Most children in the community go to the local government school for free, or to the faith-based local school for a small fee. The academic system goes until the 12<sup>th</sup> standard grade and then students apply to attend college. There is a local college in a neighboring city, but many children do not attend school, and if they do, rarely do they complete 5<sup>th</sup> standard (i.e. 5<sup>th</sup> grade).

Children often go to school to receive a free lunch and this may be the only meal they eat in the day. Parents and community leaders report that the promise of lunch is the only thing drawing students to government school. Girl children are sometimes kept from school if a family has limited resources. While it is shifting very slowly, boy children are traditionally and culturally more valued because they will not leave the home after marriage and will continue to contribute to the household. Because of this fact, parents want to invest their limited resources into boys, rather than girls, if they have to make the choice. The local faith-based school emphasizes the importance of girl's education and provides pathways for girls to learn at a low cost. Despite the low cost, many girls are removed from school to help at home or to become married.

Individuals within this community are of different faiths: Hindu, Muslim, or Christian. Religious festivals occur within the community. Weddings are large celebrations where everyone in the village attends and contributes either money or food. Young women traditionally are married by age 20 and they begin their family shortly after. The wedding of a daughter is a cultural and family milestone that is celebrated and saved for from the birth of the daughter. When women get married, they move to the home of their new husband. The financial cost of a daughter's wedding and the loss of the daughter's contribution upon marriage impact the family as a whole. Parents of girl children in this community face additional hardships and this impacts their desire to have boy children, over girl children to avoid additional financial hardship. Some young women in the community do earn their education, and break from traditional gender roles, but this is not possible for most due to the cost and difficulty in earning an income in the community.

With respect to the climate, the weather is generally hot and humid for the majority of the year. For two of the 12 months, it becomes colder and there is a specific rainy season where rain fall occurs every day. Community residents cool off in the summer with fans, and warm themselves by fire in the winter, because only the wealthy have air conditioning units. There were no heating units at any of the homes I visited within the community. In the winter it becomes very dry and the vegetation is covered with a thin coat of dust.

In the community center, there are a few shops that sell tea, rice, spices, snacks, and toiletries. There is a seamstress who has set up a shop in town who is always busy because women's saris require a blouse. This blouse is made from a piece of extra fabric

that is included with the sari which must then be cut and altered to fit the woman. At another shop, residents can recharge their cell phone minutes by visiting a phone shop. It is very common for people to have cell phones, but not as common for the phones to have internet access. For example, most of the people I interacted with used their phones for calling and taking/sharing pictures, only some young people had internet access.

Teledensity, the number of telephone connections per one hundred individuals living within a specific area, has traditionally been linked to GDP, but in this instance, it is not a relevant social index, as most of the people, even the very poor, own and use mobile handsets. This has been made possible due to a revolution in mobile telephony in India because the service providers charge a fee so small that is almost incomprehensible to cellphone users in the West.

While a few shops exist, the majority of community members purchase items for their home at the market. A weekly market provides residents with the opportunity to purchase fruits, vegetables, fish, and meats. Goat meat, fish, and chicken are the most commonly consumed meats, and vegetables are eaten based on what is seasonal and least expensive. There are set prices for items in the small shops, but for the market, a degree of negotiation is required. Residents are also able to buy other clothing and household items at the market.

Individuals in the community know each other intimately and interact with each other daily. There is a culture of spending time with neighbors outdoors and sharing a cup of tea and a cookie. Word travels very quickly in this specific community, and residents are generally aware of what is happening within families and nearby smaller villages. People have a strong sense of community, which means they all gather to discuss a social

problem. Such strong community bonds caused the researcher some difficulty in terms of maintaining the privacy and confidentiality of each research participant. Researcher strategies to maintain confidentiality included careful selection of interview location and time of interview, as previously discussed in the methodology section.

### Demographic Data

Prior to beginning the interview, demographic data were collected from all participants. Gender, education, religion, primary language, marital status, age, number of children, and number of individuals in the household were collected from both individuals who had a kidney removed and those who did not. Individuals who had a kidney removed were also asked to report the amount of money promised for their kidney, as well as the amount received. In this section, the demographic information for persons trafficked for an organ removal and those not trafficked are included in Table 2, with additional demographic characteristics described below.

*Table 2. Demographic Information*

		Person Trafficked	Not Person Trafficked
Variable		Frequency (Percent)	Frequency (Percent)
Gender		N=23	N=20
	Male	17 (74)	10 (50)
	Female	6 (26)	10 (50)
Education			
	Never Attended	11 (52)	10 (50)
	3rd to 4th Standard	5 (24)	3 (15)
	5th to 6th Standard	3 (14)	2 (10)
	7th to 8th Standard	2 (9)	1 (5)
	9th to 12th Standard	0 (0)	4 (20)
	Missing	2 (9)	0 (0)
Religion			
	Christian	1 (4)	7 (35)



Primary language	Hindu	14 (61)	8 (40)
	Muslim	8 (35)	5 (25)
Marital Status	Bangla	21 (91)	12 (60)
	Santali	2 (9)	8 (40)
	Married	23 (100)	17 (85)
	Not Married	0 (0)	3 (15)
Variable		Mean (Range)	Mean (Range)
Age/years		35 (21-60)	37 (18-65)
Number of children		3 (0-5)	3 (1-8)
Number in household		6 (3-9)	5 (3-9)
Amount promised for kidney (USD)		\$1,670 (\$366-\$4,249)	N/A
Amount paid for kidney (USD)		\$1,553 (\$249-\$4,249)	N/A

**Children's education.** For the children whose parent is a trafficked person (PTOR) or not a trafficked person (NPTOR), depending on the age of the children, there was a wide range of educational levels. Some children are too young to attend school, while others are grown and working. The majority of the children are currently attending local government school. Five participants indicated that their children have never attended school and either stay home to tend to younger children and livestock or leave home to work in a factory in a larger city.

Participants often drew the distinction between attending school and learning, as many children attend school in order to receive lunch for free. They may attend not being equipped with the supplies to be successful at school or the parents may not have the ability to monitor if the children are gaining knowledge.

**Monthly income.** Calculating the monthly income for participants in the sample was difficult due to the fluctuating availability of work dependent on season, the type of work that the individual does, and their physical ability to work. Most participants earn between \$2-3 U.S. dollars per day, but the work is not steady and is not available every day. On average, a PTOR earns approximately \$30 to \$45 monthly, which means that they work on average 15 days per month. Individuals who have not had their kidney removed earned between \$25 to 100 dollars monthly. This monthly income was difficult to report because work is not steady. The individuals who are earning close to \$100 USD per month are working outside of the community in factories in larger cities.

To illustrate this, the experiences of two individuals are provided. Puja, a 35-year-old female field laborer and PTOR, explained, *“We used to get 150 [\$2.20US] per day, sometimes 120 [\$1.75US] per day, there is no guarantee, sometimes we don’t get any work, normally, if we get work every day then we make 120 rupees [\$1.75].”* This experience was shared among many of the study participants, regardless of their status as a trafficked person. Suparana, a 41-year-old female stressed that work is not consistent by saying, *“Before I was getting work, but rarely, maybe once in every 10 days, even now only every 15 days, 8 days, 10 days.”*

**Occupation.** All of the participants are agricultural daily wage earners or housewives who tend to children and livestock. Most of the individuals work in the fields, planting and cultivating land that is owned by another person, or catch, trade, and/or sell fish at the local weekly market. Anju, a 25-year-old female who is a housewife and field laborer explained:

We are both working in order to keep our family alive, we have girl children, we are trying our best. We are working in the field, just that, otherwise what else will we do,

there is no other work except field work here. We are taking care of some goats and cows. We are trying to buy a big cow, a cow that will give more milk, but we don't have any money.

**Time since transplant.** When asked about the time since transplant, many of the participants could not recall specifically how long it had been. This lack of awareness about dates is not uncommon. For example, dates of birth are not always recorded, officially or otherwise, and few people can identify with conviction the year of their birth. Typically, questions about date-of-birth are answered as, "Say I am 35 or 40." The same is the case for the time since transplant. Participants who were interviewed provided their best guess on the length of time, with the range being from within the last 3 months to 8 years. The majority of participants had their kidney removed about 3 years prior to the interview, but some were more recent. Additional individuals who recently had their kidney removed are believed to be living in the community, but they are not currently connected with organizations in the community or with others who are also PTORs, therefore, they are more difficult to reach.

**Location of transplant.** Almost all participants (74%) had their organ removed at a large city in Northern India. The remaining quarter of individuals (6) had their kidney removed at another major Indian city while they were away from the community for work. The majority of the participants (70%) recalled where (which hospital) the transplant occurred, while the others were never aware or cannot remember. To maintain confidentiality, neither the cities, nor the hospitals, are revealed.

**Work status at time of transplant.** Prior to the transplant, most of the study participants were working full days sporadically and they had the strength to complete

a full day's work of hard labor in the community. Others were able to work full-time out-of-state at factories.

**Current work status.** Many participants (52%) are still working in their respective occupations, but for fewer hours per day. Four of the participants (17%) are completely unable to work anymore. Puja, a 35-year-old housewife explained, *“After selling, I cannot work outside, I am frightened, what will happen to me? I used to plant paddy and uproot the grass from the field, but I’m frightened, my physical health is not that good.”* Puja is suffering from both physical consequences and emotional consequences that hinder her from working as she previously did pre-surgery. Aanjay, a 60- year-old male fish trader, explained how having an organ removed has impacted his work status. He said:

I cannot work as much. I have become very weak. I cannot bend down or lift any weight. See, we have to cut the soil, lift the load and throw it another place. But I cannot do that now. I am not allowed to lift any weight.

### **Economic Environment**

The economic environment within which the individuals reside is marked by competition for scarce resources, lack of opportunities for stable employment, and inadequate and poorly funded government assistance programs that provide little more than hope to individuals and families. An individual's financial status and ability to obtain resources is linked to their susceptibility to TPRO. The presence or absence of resources serves as (respectively) a protective or vulnerability factor, because the main motivating influence in TPRO is financial/ economic. Access to resources is the most critical factor to examine when trying to understand how individuals become PTORs.

Access to resources in this community is limited for many individuals, but especially so for those who became trafficked persons.

As described in the setting above, study participants reside within an agricultural community and the primary source of work is crop cultivation. Availability of work varies based on the season. Very few jobs exist in the community outside of the agricultural sector. The few higher paying jobs that exist are unavailable to common people as they require education, specific skills and training, or connections (e.g., government jobs, tailoring).

In this community, there is a daily struggle to earn enough to provide food for the family and individuals earn what they are able to through cultivation. While work does exist, there is no stable work availability, which impacts the overall earnings of a family. It is not the nature of the work, but rather, the lack of consistency and stability in work that does not allow for financial security and saving for emergencies. Suparna, a 41-year-old female field laborer, was concerned about caring for her family, particularly since work availability limits the amount of hours an individual can work. She explained, *“Before I was getting work, but rarely, maybe once in every 10 days, even now only every 15 days, 8 days, 10 days.”*

Stable income is required to maintain a family, to provide food, clothing, shelter, education for children, and medical care for all family members. When medical emergencies arise, for example, families may not have the income to treat their elderly family member or their child. Not only are resources required for basic needs, but also for family events with deep cultural importance and significance. The wedding of a daughter is a milestone for every member of the family, not just the daughter. Families

with resources begin saving for this event at the birth of the child, and the wedding is not only the real and symbolic movement of the daughter from one household to another, but a display of status and position within the community. Weddings can also be a time where the kindness and generosity in communities is strongest, as community members band together to provide monetary support. For some, an impending wedding is a constant source of stress, particularly when the family does not have adequate resources and is unable to save for the upcoming life event. Abhishek, a 38-year-old male who was not working at the time of the organ removal, but now works some in the fields, explains how the marriage of his two daughters was directly linked to his kidney removal. In this instance, the lack of resources and the pressure to provide a wedding for his each of his two daughters pressured him to sell his organ in response.

We are poor people, we didn't have anything. How was I going to give marriage to my daughters? I did it for their marriage. Otherwise, we, we didn't even have any land, I had two daughters, how was I going to give the marriage? I have two daughters and one son.

Conversely, individuals with resources can rely on the sale of land or other tangible items to cover the costs of weddings or emergencies.

Land is a resource that can provide economic and emotional security to families. Almost all of the individuals that were interviewed did not own land, but either worked on other's land or rented plots of land to cultivate. Owning land allows the family to have a resource to fall back on in situations where they need money rapidly. Within the larger economic environment, those with land possess a resource that can be traded or sold in the event of a family emergency or for planned event, such as a wedding. It is a tangible resource that can protect an individual from being susceptible to organ trafficking. Sonia, a 38-year-old female who works for the local community organization described how

their family land protects them from having to sell their kidney. In this instance, Sonia and her husband are struggling to educate their son. Her work as a community social worker is not steady and does not provide a livable wage, not unlike others in her community. She explained how her land can support her son's continued education and she has an option to sell the land, as opposed to her kidney:

He finished the third year; we need 1 lakh 60 thousand rupees [\$2,335] for our son's schooling, so my husband is trying to sell the land. If a broker comes to my husband and says you should sell your kidney, your land won't be wasted, maybe my husband would be ready to go sell it. If someone is telling him this, that he can sell his kidney, I will tell him not to go. We will borrow the money from somewhere, somebody else, and then pay back. I can sell my land or our jewelry and then we will keep our son in school.

Sonia described how, given her possession of land and jewelry, her son can continue to attend school. Unfortunately, individuals or families in this community rarely have this resource (land) available. Lack of land ownership is just one indicator of a deprived and suffering economic environment and of the struggle for individuals and families to survive day to day. When speaking with individuals who have sold their kidney in response to an emergency, generally because they lack other economic resources, they often cited their lack of land as a contributing factor. Susmita is a 30-year-old housewife who also works in the field periodically. Within her family, there was no land to pass down from past generations and her husband's family also lacked the resource. She describes how land impacted her economic situation, and subsequently her status as a PTOR.

We don't have any land, we are working people. With the money that we get from work, we eat. My parents don't have land and my husband's parents don't have land, this was the reason I sold the kidney.

Individuals in the community are sometimes connected to borrowing and saving organizations. For-profit companies, such as banks and lending companies, and non-profit community organized groups exist that offer individuals the ability to borrow and save money. These organizations provide avenues for people to plan for future events, for example weddings of daughters, by connecting with either a bank or a community organization where a group of individuals with a common purpose gather their money. Within this specific community, groups of women gather, depending on location or purpose, and they develop procedures for saving funds, as well as seek out work for their group.

Groups are often formed along cultural or skill lines, with women gathering to both save money and to advocate for alternative and stable work in the community for women. Organizers with the local community organization began this process by gathering women to discuss how borrowing and saving amongst the group could benefit individuals and families. The purpose of the group is to empower women and to provide a safety net for families in the case of a large life event or an emergency that requires money. If an individual has livestock, they are able to borrow from other individuals or from companies. Lenders often determine if the person or family can borrow money based on their tangible resources (e.g., livestock, home) or their reputation within the community. Often lenders will determine whether or not individuals own livestock before providing the loan; the livestock is then viewed as collateral if the individual cannot repay the loan. When asked how she would handle a financial emergency or a planned event, such as a wedding, Payel, a 35-year-old female who works as a field laborer and maker of homemade wine, said:



I can borrow money somewhere, I will ask the people if I can borrow the money. I can also sell my animals and collect the money and treat him. We have only one daughter and when she was pregnant, on the day of delivery, they did the surgery and took out the child. We had a cow, we sold the cow and gave the money to the hospital for her medicine and for her surgery... if you are not able to pay back, they will not trust you and loan you the money. Anyone is ready to give us money if we borrow, because we get the money and then pay the money back. We always need money and we always need other's help. We have to get the money and then pay back at once. When they need, we can also help.

The initial resource of livestock that Payel's family had enabled her to obtain the loan and subsequent loans are dependent on her ability to repay the initial amount.

Another individual who was not a person trafficked for an organ, explained the system of borrowing money within the community, including the specific unwritten rules. For Piya, a 30-year-old female who sells rice wine from home, it was the presence of livestock that allowed her to obtain the initial loan.

Nowadays we are borrowing and getting the money. If we are not able to pay, they will take things and go, they will take my pigs and goats and take them and go. If you have anything at home, they are able to give to you, and if you can't pay back then they will take your things from home. This is the rule: if you are taking from others then they are ready to give me money, if I can pay back (these are neighbors loaning money to each other in exchange for animals), we keep this plan in mind and we are keeping something at home in case.

Individuals and families who have no resources are excluded from participating in borrowing and saving organizations because initial buy-in capital is required. It is important to note, also, that individuals reported that they were only able to borrow small amounts of money at a time. This could protect them from a small emergency, but not necessarily support them during significant life circumstances. For example, Payel's family has been able to borrow on numerous occasions, but sometimes only small amounts. She explained this by saying, "*Many times we have borrowed money. The*

*number of times I don't know, 50 rupees [\$0.75], 100 rupees [\$1.50], here. When money is in the hand, we will give it back."*

Both land ownership and connections to borrowing and saving organizations are protective factors, ways in which individuals can get capital on a regular basis or during an emergency situation. It can be predicted that money will be necessary for the wedding of daughter. Connection to a borrowing or saving organization enables the individual to procure funds over time to prepare for a large life event like a wedding. Families who suffer emergencies, such as a sudden illness of a family member, need access to large sums of resources immediately. Borrowing and saving organizations in the community currently offer small loans, some may cover the costs of a sudden medical illness, depending on the illness, but some may not. The reach of borrowing and saving organizations is limited and often the amount available is insufficient. Families generally need to prove a form of collateral, such as livestock or a suitable home, to receive the loan. Women can become involved in working empowerment groups, but the shared nature of the group does not allow for individual women to get a large proportion of the group's funds. Kidney sales provide individuals with a large sum of money relatively quickly.

### **Government Response**

In response to the myriad economic needs that exist across India, government programs were developed. National, state, and local government programs were created to provide resources and access to work to community members. In response to rural poverty, the India's government created livelihood programs that would guarantee an income for individuals for a minimum of 100 days per year. The Mahatma Gandhi

National Rural Employment Guarantee Act (NREGA) of 2005 is a law that is intended to provide work for individuals in rural communities and to provide financial security for unskilled workers (Ministry of Rural Development, 2005). NREGA provides 100 days of work to increase wage security as part of citizen's right to work. This program has been lauded by the World Bank (2015) as providing the world's largest social safety net program. This government assistance program is commonly known as "100 Days Work." Data from this study, however, indicate that NREGA fails to provide the intended wage security to some non-skilled laborers, according to some individuals who participated in this study. Rohan, a 35-year-old fisherman and field laborer explained his frustration with the government program by saying:

NREGA? Where is the work? I hold a job-card (required to get at least 100 days per year of work in rural areas) that is seven years old. In these seven years, I have received two days of work under the scheme.

A common theme within the data was general disappointment in the 100 Days Work program, highlighting the need for full funding of the program, as community members like Rohan are willing to work, but the funds to support the program are inadequate. Some individuals, like Rohit, a 36-year-old male carpenter, have worked under the program but have experienced long waiting periods to receive payment for work completed.

All that is there [government work programs], but where is the money? The final issue is money. There are times when we get the 100 days job but the payment just does not come, it takes six months, even a year to get the money. So how do we poor people manage? That is the problem.

The guarantee of employment and wages for 100 days could serve as a protective factor against TPRO, but data indicate that the program is not effective in the community. The NREGA government program exists, but does not function, at least in this particular

community, as a poverty-reducing program. It is unclear if other factors, such as individual knowledge about how to engage with the government program, are also impacting its effectiveness in the community.

Other general community-level assistance programs, such as housing assistance and funds designated for older individuals, are present, but my data suggest that these programs are not equitably distributed. Individuals complained that the government is currently failing to provide financial assistance to the most vulnerable members of the community. It is the general perception in the community, as confirmed by data, that wealthy families are the beneficiaries of government assistance, instead of families with a greater need.

Study participants frequently commented on how they were promised goods or services and never received them. Many interviewed indicated that with sufficient government help through fully funded, adequate programs, poverty could be reduced and TPRO could be prevented. Rohit faults the government for failing to provide solutions for those in poverty, particularly those who are most vulnerable to kidney selling. He was disgusted with what he perceived as an unfair, imbalanced system that benefits the rich and neglects the poorest in the community, leading individuals to make decisions they otherwise would not make.

Government is saying we will do it, we will make you houses, we will give you something, but everything is going to the rich people. They are saying that we will make your ration card BPL (below poverty line), they are living below poverty, but the card is not there. Rich people have money and land, but they have a BPL card, they have only have to pay 2 rupees [\$0.03] for a kg of rice, but we have to pay 5 rupees [\$0.07] per kg. Poor people, we have no other choice, we are not getting any opportunity. We have no choice other than to sell the kidney.

Similarly, Asmi, a 31-year-old housewife and PTOR, drew clear connections between the lack of government support and kidney sales, as well as the unfair distribution of services within the community.

If the government had given me work, then I wouldn't have sold. I have hope that the government will do something for me, after selling my kidney. They took the names of those who were victims and we were blamed. We were supposed to get some help, but they gave it to other people.

A neighbor of Asmi's, Priti, a 25-year-old female housewife, had her organ removed. She explains that not only is TPRO a financial issue, but it is one that can be positively impacted by adequate government response.

I am thinking if the government is giving some facilities to them, some work so they shouldn't have to go, then they won't go. Without this, people are in need of money, of course they will go! They don't want to go, but they have to go. There is no help. If they give something to the poor or they do something for them, then it will be good for them. If they get a chance, it will be nice for them and they won't go for this, but they aren't giving anything. Because of that, they are going [to sell their organ].

For poor individuals living within this economic environment, without the support of the government or the opportunity to obtain a steady income, organ sales have become an alternative revenue stream used to mitigate life stressors and fund planned events.

### **Financial Motivations**

At the core of the practice of trafficking of persons for the removal of organs (TPRO) is financial need. All PTOR study participants indicated that their main motivator was financial, whether it was to solve an acute financial problem (family illness), to fund a planned event (wedding), to provide daily sustenance for their family (food), to seek a better life (purchasing of home, or land), or to provide for their children (education). Each idiosyncratic need created a similar situation across the sample: they needed capital, so they sold their kidney.

All trafficked persons were asked to describe their motivation for organ removal, particularly what played a role in their choice. All individuals, except for one, had an understanding, albeit limited, that their kidney would be removed and that they would receive compensation for it. One trafficked person, Mitu, was not aware that his kidney would be removed and the transplant occurred when he was undergoing tests for a separate medical condition. In this instance, Mitu was seeking work outside of the state, as stable work in the community was not available at the time. The individual who arranged for his work also served as a broker for kidney trafficking. Out of state and away from family, Mitu was convinced of the need for the surgery, completely unaware that his kidney would be removed. In this case, he received no compensation for his organ; in this, he differed from all other interviewed individuals who had their kidney removed.

All other PTORs explained how their current and specific financial needs motivated them to seek out a kidney sale opportunity. Balu, a 19-year-old who has not sold his kidney, but who lives within the community, explained it simply saying:

People do not have enough money. So they feel, if I can get 300,000 [\$4,358] selling a kidney, I can solve this or that financial problem. So they do it. They earn 100 [\$1.45] per day, on days when there is work, which some feel is not enough, so they fall into the trap.

Balu is intimately aware of the financial struggles that lead to TPRO because he has both family members and friends who have had their organs removed. While he was only nineteen at the time of the interview, he was knowledgeable about factors impacting kidney sales and was repeatedly exposed to loved ones and community members who sold for various financial reasons.

## Choice

The presence or absence of choice emerged as a theme within this study. Each individual's understanding of available choices at the time greatly impacted whether or not they became a PTOR. When options such as selling land or livestock, or working overtime to earn extra income were not possible, individual PTORs sought out alternative sources of income. Individuals in the community often felt extreme financial pressure and felt that they had no options but to seek the available opportunity of kidney sales. Puja, a 35-year-old female field laborer, described her understanding of her options at the time by saying, *"I was feeling afraid. I had so much fear, but what was I going to do? I went because I needed money, nobody forced me to go, I had to go."* For some, like Puja, a general need for money existed, a need to have the funds to be able to support her family and provide food, clothing, and education for her children, while others shared the specific need they had. Tapas, a 59-year-old male fruit seller who sold his kidney, reflected on how he was specifically motivated by the need to marry his daughters. He viewed his financial situation as the reason for organ removal, noting that he had a problem and a solution.

When I heard about it, I was thinking, my two girls are there and I have to give them marriage and if I give them marriage then I need money, so I went myself. I had no money, I went to [broker name removed] and told him, "You guide me, I want to do this. If I get money, then it will be helpful for me."

Closely tied to the theme of access to resources, the real and perceived options that individuals felt that they had for solving financial and familial problems in their life emerged as another theme within this study. The option to give a kidney for money for some felt as though it was not an option; it felt compulsory, that there was no real option for them. Some of the non-trafficked persons expressed the same observation; many of

those who gave their kidney did not have any other options. Promit, a 45-year-old

NPTOR male fish seller, understood that for some individuals, there was no other option:

I cannot say anything against them. I know only one such person who had to sell his kidney. But he didn't have an option. He had two young daughters to get married and he had no money, so he did it. He somehow got the first daughter married off, but for the second one he had to sell his kidney.

Not all NPTORs interviewed in the community shared the same sentiment as Promit and understood how options were limited for many PTORs. Some individual NPTORs expressed disapproval and drew distinctions between themselves and those who had an organ removed.

### **Altruistic Motivations**

While all individuals who were trafficked for an organ removal (PTOR) cited financial reasons, in a few cases, secondary motivators were discovered. As described in Chapter 2, living organ donation is predicated on the principle of altruism, a lifesaving gift from one individual to another. For some research participants, the act of extending another's life was also a motivating factor. In no cases was altruism the sole motivator, but rather, a secondary reason for kidney removal. All individuals were asked to share information about anything that motivated them to have their organ removed. Ajay is a 21-year-old man who was not working at the time of the interview, but he had previously worked in the home of a woman in a nearby city. As a domestic helper, he spent long hours at his employer's home and developed a relationship with the family. Understanding that many in his community had received compensation for their organs, when he became aware that she was in need of a kidney, he volunteered for two reasons. His motivations are described below.

I was working in the house of the lady who got the kidney. We had a relationship like



brother and sister. They told me that they needed a kidney and you need to search for someone and I told them that I would give it. I said I am also poor and facing financial problems so I will give. I didn't say anything to them about the money or ask them for a certain amount, whatever they wanted to give is what I thought they would give me. I donated my kidney because I wanted to save her life. We have certain rates for goats and chickens, but I did not ask for a certain rate for my kidney.

While Ajay had an expectation that he would be compensated, he also desired to help the family. As explained above, financial stress and the promise of compensation was the driving force for all individual PTORs, but a select few also shared that a benefit was helping to save the life of another person. These individuals generally had existing relationships with the organ recipients and had personal, first-hand knowledge of the other person's need for a kidney. It was the relationship built between the donor and the recipient prior to the organ removal that, aside from the financial benefit, was a factor. In a similar situation, another young male who worked as a domestic helper, Ganesh, expressed that the relationship he had established with his employer's family motivated him, at least in some part, to give his kidney.

I was thinking that if I can live with one kidney and then save her life, I can say that with my kidney, someone is living. I told my boss that I will give it to her. The lady didn't have any brothers or sisters; she also didn't have any children. She had only been married two years. I liked her so much. She was treating me like her own brother, she was washing my clothes.

In the case of Ajay and Ganesh, they both described the "brother-sister" relationship that existed between themselves and their employers. They felt like members of their family. This relationship is what is cited as a motivating factor. Both men felt a sense of belonging and that they were part of the family, leading to their decision to provide their kidney to the ailing individual, with the expectation of receiving compensation. In the end, both Ajay and Ganesh received compensation for their kidney.

Results of the interviews suggest that this relationship between the donor and recipient would not alone be sufficient in motivating the PTOR to give their kidney without compensation. Without the promise of compensation for the organ, Ajay and Ganesh would not have been motivated to give to the recipient, despite the established relationship and desire to help the individual. Their desire to help the individual was a secondary condition. . When asked whether or not she would have given her kidney without any financial benefit, in the spirit of altruism alone, Misha, a 45-year-old housewife, explained that while it was a positive experience to help another, that she regretted giving her kidney. Misha said, *“At that time, we were proud that we gave life, but now we feel sad, we don’t know why we went to give like this, regretting this.”* This regret, in general, stemmed from disappointment, anger, and shame related to loss of physical strength, and various emotional and economic consequences. This was a common expression post-transplant, as most individuals regretted their decision. Ajay expressed regret in the form of sadness and disappointment, particularly at the difference in the relationship between himself and the recipient/”sister” post-transplant. He explained that he has limited communication with the family and is unable to work in their home due to his physical restraints, as a result of the surgery.

While regret and the individual experiences pre and post- transplant will be discussed further in Chapter 7, it is important to understand that acts of altruism were not done out of pure altruism, but rather within a larger financially constrained context.

### **Bodies as Economic Tools**

Pride from the choice to not have an organ removed for compensation is a theme that arose within the data from people who did not get trafficked for organ removal.

Findings suggest that non-trafficked persons had real or perceived choices that impacted their decision. One, Dipan, a 49-year-old fish seller, stated, *“I am proud that I did not do this. I live by my own hard work. I do not take the easy option out.”* From Dipan’s perspective, those who sell their organ choose to do so despite the availability of hard work. He draws a distinction between himself and others, as he earns through hard work, as opposed to organ removal. It is in this perceived choice to utilize the body in this particular way that differentiates him from others who utilize their body differently to survive. For him, his choice serves as a source of pride. Dipan believed he had the option to work harder to earn additional income, whereas others did not perceive this as a real option.

For other individuals who did not have a kidney removed, pride arose from their decision to never have a kidney removed, despite financial hardships. Amit, a 38-year-old fisherman, adamantly expressed his disapproval of kidney sales and explained that regardless of struggle, he would not sell a kidney. It is likely his own personal view of kidney sales that informs his decision, and not necessarily the presence of resources that protects him from TPRO. However, it is important to note that those who were not trafficked may have possessed some additional resources that gave them financial or emotional security that allowed for this decision. Amit explained his decision simply by saying, *“You have no idea of the kind of hardships I live with, and yet, I will never ever think of selling my kidney. I would not even utter that word.”* He explained that these struggles and hardships can be reduced, in his mind, with the use of his hands and feet to continue working hard.

Two neighbors who both work as fish catchers and sellers shared similar sentiments, noting that their own bodies, their hands and feet, are what they utilize to survive. The body literally, in these instances, is a tool for economic survival. This is not unlike the persons who had their kidney removed, except that the utilization is different. *“Me and my family believe that we shall only depend on our hands and legs to work and get what we can, save as much as possible, and live the rest of our lives this way.”* This sentiment was shared by another NPTOR.

I have my two hands to work with, so I will work to earn what I need. If I can get my needs fulfilled well, that be it, otherwise may be I will die. But I will never sell my kidney.

Differences in how NPTORs view themselves and their bodies in comparison to others, particularly those of other cultures and religions living in the community, can be seen in descriptions of their desire and willingness to work to solve financial problems. Piya, a 30-year-old female who sells rice wine from home explained:

Any work is good, we are Santal people. Any type of work in the field, we will do it. If you have will, then you can do any work, willingness is there and needed. If you have willpower, then everything will be possible.

Piya explained that those within her cultural group seek work and that willpower allows people to overcome difficult financial circumstances. She believes that it is her desire to work that protects her and others within her culture from having an organ removed. While this likely influences her status as a trafficked person, Piya's possession of livestock cannot be ignored as it represents a tangible resource that can be traded for a loan that allows for increased financial and emotional security. Individuals without livestock may also value hard work, but given the unavailability of steady work and lack of resources, they may feel merely being willing to work hard is inadequate for survival.

These differences in world views, in some part, explain how some individuals become trafficked persons, and some do not. In interviews with those who were trafficked and those who were not, the theme of the body as an economic tool emerged. For those who are trafficked, the sale of their organ represented the only option they saw to solve acute and chronic financial problems. This worldview, however, was developed within a difficult economic environment. This analysis of the use of their body to generate capital is not mentioned to place blame, but rather to further understand how individuals in this community use their resources to survive. Some individuals view their body and its ability to engage in hard work as their method to alleviate financial stress, while others who felt they lacked options, utilized their body differently.

Regardless of trafficking status, all individuals were living in the same economic environment, and while some had additional resources such as land or livestock, the difference in worldview seemed to impact choices about organ removal. How can the body be used to survive? For some individuals, exertion of the body through physical labor brought financial survival while for others, it was through kidney removal. It is difficult to compare the intentions and decisions of these two groups, however, because the availability of choices at the time varied greatly. Choices empowered individuals to be able to make a decision to never sell a kidney and to depend on their body to work, whereas others felt that their financial survival could only be ensured through organ removal.

## **Chapter 5. Findings-Cultural and Societal Influences**

In this chapter, the cultural and societal influences that impact the occurrence of trafficking in persons for the removal of organs (TPRO) will be presented. These influences include: a) gender and vulnerability; b) the impact of family dynamics on decision-making; and c) the role of community understanding and broker presence.

### **Gender and Vulnerability**

Based on study data, girl children and women in this community are more vulnerable to trafficking strictly due to their gender. As mentioned in Chapter 4, women and parents of girl children face additional hardships based solely on the gender of the individual due to the culture of valuing men over women. Girl children are often seen as financial hardships because the culture requires that families pay for the wedding of their daughter, and following the wedding, the daughter will leave the parental home and cease to contribute financially. Because of this, girl children are born vulnerable in this community. In a resource starved environment, parents may value boy children over girl children because boys can engage in the economy more than girls, due to the nature of the work. Boy children may be given more opportunities for education, as they are viewed as greater contributors to the family. Men are also valued more within this community partially because of their ability to work within the agricultural setting without limits. Gender impacts an individual's ability to work and limits their capacity to leave the home to seek work.

**Gender and work availability.** As described in the previous chapter, the lack of stable work availability in the agricultural community in which this study was conducted, as well as the lack of government response to poverty, impacts the occurrence of TPRO.

While men and women participants described the struggle to survive financially in the community due to seasonal work and government programs that do not pay, women PTORs were in especially difficult circumstances. Women in this community have a limited scope of work availability, and therefore, they have limited access to resources. Women are traditionally housebound and they manage the household by caring for the children and any livestock that the family owns. Due to the limited availability of hard labor, many women are excluded from the only work available. While some female participants indicated that they were able to engage in hard field labor as men were, many more explained that the strength required to complete the work precluded them from participating. One of the study participants, Asti, a 45-year-old housewife, described her daily duties and explained that she is unable to participate in the agricultural economy as men, and very few women, do. Asti described this by saying, *“I am a Santal lady and if they are telling me to put the mud on my head I can’t do this, I’ve never done this work, I haven’t gotten used to it, so I can’t do it.”* Asti was not accustomed to the type of work and the requirement for her to work in the fields never existed. In this quote, Asti is referring to the only known solution for women to gain more income, which is to work in the agricultural sector, which she is unable to do. Beyond self-selection out of the agricultural sector due to the strenuous nature of the work, culturally in this community generally women tend to the home and men work outside of the home as field laborers, fisherman, or fish and fruit sellers. The women that do work outside of the home only seldom assist their husbands or family members at times of large harvest.

**Gender and family obligations.** Due to disconnection with the formal economy, it is difficult for women to earn an income within the community. While two study

participants did produce and sell homemade wine from their home as a source of income, this is very uncommon amongst the study sample. Rearing livestock such as cows, goats, and pigs does generate income, however, few families, particularly those where one member is a PTOR, own substantial amounts of livestock. Samaira, a 22-year-old housewife and NPTOR, described what many other study participants said, that their daily life involved remaining at the home. Despite caring for children and in-laws, the women in the study explained that they “*do nothing*” during the work day. Samaira said: “*I am at my house, what work am I doing? I don’t have any work, what work will I do? My desire was to have a cow and I could graze it.*” Her description is only accounting for income-generating work and does not include household or child rearing-related work. Both women who were trafficked persons and non-trafficked persons described their desire to contribute more to the household financially and their wish to do this through raising livestock or from new programs developed to support women’s income generation in the community.

A connection between the lack of work available for women and the incidence of kidney selling in the community was established through interviews with women who were both PTORs and NPTORs. NPTORs, in particular, also recognized how the lack of work for women is leading to increased instances of TPRO. This knowledge was gained through interactions with family members and neighbors who were women who had their kidney removed for compensation. Anika, a 26-year-old housewife and sometimes field laborer, shared this observation and offered suggestions on how to prevent women from becoming trafficked persons. Specifically, she described how a lack of income leads to organ sales.



Maybe poor girls are going. There are no other ways to make money except for this. If we are able to help them, then they won't have to do this. We can try to tell them that they may have to go to jail. We need to help them so they won't go.

Anika is not alone in her observation. Many women PTORs described how their inability to earn an income that was on par to that of their husbands made them more susceptible to trafficking. Puja, a 35-year-old woman who sometimes worked as a field laborer before organ removal explained:

If I would have had any work, then I wouldn't have gone. Ladies don't get any work here. I wouldn't have had to go, there was no work. There is pipe work now, but then there was nothing. Ladies can't work as many places. There were some places before but not many, there was only field work. He is a man and he can get work if he can work. Men are free to work anywhere, here and there, ladies are not free to work everywhere. Ladies don't have as much strength. We have to cook, husbands can leave and go outside to work. Ladies can't leave their children, most of the work at home, ladies have to do. Also if something happened to him, then they would come and attack me, they would blame me if he had gone.

Puja drew connections between her inability to work and her kidney removal, explaining that with increased opportunities, she would have been contributing to the family financially and would not have felt pressure to sell her kidney for overall family survival. At the time, Puja described how her husband intended to sell his kidney, but given the need for his continued strength post-transplant, she chose to sell instead.

He [husband] was working in their house. He was supposed to give and he told me this, so I told him that instead of you, I will give, he was supposed to give. If he would have given, then it would have been difficult for us because he is a boy and he wouldn't be able to heavy work if he gave. I'm only at home cooking and sitting, I don't get work every day. I told him that I would give, he is a man and he has to work every day and feed the family. I am a lady, for me it's no problem. I only go for work sometimes. I just told him I will go.

Individuals described that they were "*just sitting at home*" and "*just cooking*" and for that reason, among others described in this chapter and in other chapters, some women became PTORs. Their family need for money and their understanding of their

ability to earn an income in the economic environment in which they were living led them to have a kidney removed. Misha, a 45-year-old housewife, who knew the recipient at the time of the organ removal, recognized her husband's role in the family to provide through hard labor. For her, she was at home and was willing to take the risk of reduced physical strength post-transplant, a risk that was too high for her husband as he was the main provider. Misha explained: *"I am woman and I only cook, I will give so that you can work and feed our family, I'm just staying at home and I can give, if my husband is not living then how will we live?"* She understood that she was limited by her gender and that selling her kidney would allow for her to contribute in a meaningful way. In a similar sentiment, Susmita, a 30-year-old housewife who lacked land resources and support from family, expressed how the gender roles in her family impacted her kidney sale.

I told my husband that I am at home simply sitting, I will give, it is no problem, then you will work and you will feed us, you have to work hard, if you are going to give then you won't be able to work hard, for me I am just sitting.

**Abuse and TPRO.** For some PTORs who are women, it was not a sacrificial act, but rather, they received pressure from their husbands to remove their kidney. This pressure presented in the form of harassment, physical abuse, and verbal abuse. While this was uncommon and only occurred in two of the cases of the women PTORs interviewed, it is important to understand how their vulnerability and lack of power due to their gender and position made them particularly susceptible to TPRO. Suparna, 41-year-old female housewife and sometimes field laborer, explains how she felt pressure from her husband to generate income and that this pressure led her to seek out an opportunity for kidney sales. The stress that Suparna was feeling, coupled with the treatment she was receiving from her husband, led specifically to her organ removal.

My husband used to be mean to me, and scold me, and torture me and the children. He used to say: How will we manage, how will I manage alone? He said that only he was working. Even with 50 [\$0.75] how can we all eat? He used to drink, he used to fight with me too much. I was thinking about whether to leave him or my children, but if I leave then where will I go? I wanted to leave but I couldn't. I was thinking if my husband wants money then where will I get the money? I thought that I will sell the kidney and I will get the money and give it to my husband.

While Suparna felt pressure from her husband, she expressed that ultimately she sought kidney sales to alleviate financial pressures and in an attempt to mend the relationship between herself and her husband. Ami said that she was forced to have her kidney removed by her husband to pay his debts from previous purchases. Ami did not realize until years post-marriage that her husband was maintaining a separate household with another wife. When she confronted him, he threatened to remove her and her children from the home. With nowhere to go, she remained in the situation and subsequently had her kidney removed. Ami shared that her husband's other wife also had her kidney removed and that the husband retained the payment in both cases. In this case, Ami was limited by her ability to leave the marriage and seek better opportunities for herself and her children and she described being "*stuck*." Suparna described a similar thought above by saying, "*If I leave, where will I go?*" Both Suparana and Ami were in situations where, given more economic and social capital, they could have chosen to not have their kidney removed, but at the time of the removal, they were attempting to survive within their family unit and economic environment.

While not all women who were PTORs felt forced or pressured directly by their husbands, most felt pressured by their financial circumstances and their limitations. Data suggest that these women would have made alternative choices if given the support and opportunities to do so. The opportunities could have included methods to earn additional

income and to participate in the formal economy, specifically work that is designed for women that could be completed at home. Both men and women study participants noted the lack of opportunities for women and suggested the government and community-led programs could reduce the incidence of TPRO.

Family dynamics played a role in all of the cases previously described where women had their organ removed. Family beliefs and understanding of TPRO and the degree to which family members were involved influenced all cases that have been or will be presented, for both women and men PTORs and NPTORs. The role of the family in the decision-making process cannot be overstated, as data suggest that family support or opposition to kidney sales strongly influenced family and individual outcomes.

### **Family Dynamics**

Analysis of findings indicate that family members can and do influence individual decisions with regard to trafficking in persons for the removal of organs (TPRO). In most cases, families influenced or attempted to influence their loved one not to have an organ removed, whether through a family pact, or through a reminder of the known risks and consequences post-transplant. For some families, an informal pact existed where each member of the family agreed to never have an organ removed. A theme amongst many of the non-trafficked individuals was that their families as a whole had made a decision to never sell a kidney. Anamika, a 37-year-old female field laborer, explained that her family had discussed at length the opportunity to sell a kidney. Equipped with knowledge of the consequences from a neighbor's experience, Anamika and her family were steadfast in their decision. She explained: *"We have discussed this, that it is possible that if we sell a body part, we will surely become weaker. So we shall never do this."* The

basis for their decision was the potential inability to work in the future, which was commonly expressed in the interviews with NPTORs. This belief links back directly to the individual understanding and worldview of the use of the body for economic survival, as discussed in the previous chapter. While an individual's decision to sell their organ is complicated and involves various factors, family opinions influence the thought processes of many non-trafficked persons. Balu, an 18-year-old male living with his parents at the time of the interview, had previously discussed the possibility of receiving compensation for a kidney. He explained that his parents did not support this opportunity by saying: *"Both my parents were opposed to this. They said, if you sell a kidney, you will never get it back and you will become weak, so how will you work and earn your living?"* Balu, in particular, has known numerous PTORs and has knowledge of the process, as well as connections to brokers who facilitate the organ transfer. Regardless, his parents were adamant that this was not an option for their family. To further illustrate the role of the family in decision-making, the decision of Dipan, a 49-year-old fish seller is included: *"No one talks about this. My family and I were united about not anyone selling a kidney from the family. See, I will not allow anyone in my family to sell a kidney."* For Dipan, as the head of his household, he has gained the support of his family members in the opposition of kidney selling.

Family opposition to organ sales was not only a theme among those who were not trafficked, but with almost all individuals who were interviewed, regardless of trafficking status. The families of the individual PTORs also attempted to dissuade and prevent their loved one from selling their kidney, but they were unsuccessful in their attempts. The

wife and children of Aleek, a 45-year-old field laborer and father, tried to prevent him from selling his organ, but their pleas went unheard.

I told my family I was going. My wife was pleading, holding my leg, saying don't go, don't leave us alone. My children were also pleading, if you die then who will listen to us? I didn't listen. The only thing we did with that money was buy food.

Puja, a woman who gave her kidney in replacement of her husband's, explained that her mother and her husband urged her not to have the surgery. Puja described how she became angry at her mother's suggestion and ultimately disregarded the opinions of her loved ones.

My mother tried to prevent me. She said your children are small, don't go to sell your kidney. I wanted to beat my mother because she was telling me this. My mother was thinking that I will beat her if she tries to prevent me. My husband couldn't say anything... he was telling me that there is no need for you to give, but then I told him it is no problem.

Data from NPTORs indicate that family discussions can influence individuals to avoid selling an organ, but data from PTORs also indicate that decisions can be altered and made based on the exact circumstances and current financial strain. The difference in the role of family suggests that family opinion and discussion regarding kidney sales could potentially help prevent TPRO from occurring within some families, but within other families, stronger influences existed. These influences are undoubtedly financial in nature. In the case of Puja, she felt that her financial situation and her status as a woman, unable to earn an income in her community, greatly influenced her status as a PTOR. Given solutions to solve her financial problems, she likely could have accepted and abided by the advice of family members to avoid kidney selling.

Despite their family member's best efforts to prevent it from happening, other PTORs indicated that they gave their kidney against everyone's wishes. Rohit, like Puja,

had serious financial troubles and could not find a solution outside of selling his kidney.

This sentiment is in line with the motivations of the vast majority of PTOR experiences described in the previous chapter. Rohit explained:

Everyone tried to stop me, my wife, parents, even my father said I will give you my property. He said that he would write my name on his property, everything. I was stubborn and didn't listen to anyone. What I want to do, I will do. I wanted to sell the kidney and get some money. They tried to prevent me, but I said if you prevent me, then you can solve my problem? Can you solve my problem? What is lacking in me? Can you solve my problems for me? Anyway I will sell my kidney and I will be freed from this problem.

The degree to which a family is involved in the decision-making of the individual varied greatly, from fully involved and resolved in opposition, to completely unaware of the family member's intention to sell their organ. Individuals who did not share any information with their family at the time explained that their family could have played a pivotal preventative role if they had shared their decision pre-transplant. Simply, family members could have influenced trafficked persons prior to the transplant, if they had been given information earlier. One trafficked person described how his family could have intervened in the situation if they had awareness and knowledge at the time. The 25-year-old male field laborer explained, *"If my family knew before then they could have stopped me, but I had already done it. There is no use in preventing me after I've done it, if before then, they could have stopped me."* Despite the fact that the family was not successful in deterring the individual, the theme of family influence is important to consider in the full scope of contributing factors, both vulnerability and protectiveness.

To this point in this chapter, the role of gender and family knowledge on TPRO has been examined. The second half of this chapter will explore the impact of community

knowledge and the impact of the presence of brokers on the way in which the risks and benefits of organ transactions are viewed and understood.

### **Community Information Sharing**

The specific community in which data were collected is one where individuals interact with each other frequently out of choice and also necessity. Families and individuals know each other, work with one another, live in close proximity to each other, and spend time together. This fact influences the way in which information spreads and people become aware of what is happening within the community. Study data indicate that community awareness about trafficking in persons for the removal of organs (TPRO) impacted the occurrence of organ removal.

The source and type of information that people receive impacts their understanding of TPRO and to a degree their susceptibility to becoming a trafficking victim. Participants were unaware at the time of the physical, social, or economic consequences of having a kidney removed. All participants were asked to describe what they knew about TPRO and how they developed this knowledge. Information is shared through word of mouth, newspapers, and through the presence of brokers in the community who may seek out specific individuals. The role of brokers will be discussed in Chapter 6 and this section will focus specifically on how information is shared and how it may have impacted decision-making.

Information primarily is disseminated from one individual to another directly through word of mouth or observation. Many families have been living in this community for generations. While not exclusively, many of the homes in the village are congregated according to the specific type of agricultural work that the individual does. This is largely



based on the geography of the community. For example, many individuals who catch and sell fish live in the same area of the community due to their desire to have close proximity to the bodies of water in which fish exist. This is a critical factor in understanding how information spreads and how the heard and viewed experiences of neighbors can impact decision-making, particularly with regard to TPRO.

Every individual that was interviewed either knew a person trafficked for organ removal personally or had knowledge of individuals in the community who had sold their kidney. Simply, *“everyone knows this in the villages,”* shared Aanjay, a 60-year-old fish trader who is a PTOR. Dipan, another fish seller who is a NPTOR and living close to Aanjay, explained how his family became aware of kidney sales. He described how it would frequently occur in the community and that *“we heard other people were doing this almost every now and then, so we got to know of this.”* It is unclear whether he learned specifically from Aanjay or from others. Data indicate that people outside of this specific fishing village within the community could also identify those who had sold their kidney and that it had occurred among those working as field laborers. Working as a field laborer, Arjun, gained knowledge of numerous individuals who have sold their kidney. While the information is not first-person, he frequently heard of this happening. Arjun explained, *“I know four or five such persons. I have never seen them to go sell, nor known when they came back. But it was hearsay from which I got to know that so-and-so has sold his kidney.”*

Beyond word of mouth, participants also indicated that they learned about kidney selling from cases that were highlighted in the news, or from newspaper advertisements. Only one participant learned of the opportunity through television, but it is worth noting.

At the time before organ sale, Puja had a dire financial situation and was struggling to provide food and clothing for her children. A specific news program alerted her to the possibility of earning money for the kidney. Puja explained, *“I have heard from people. On the TV also they were showing it. From listening to the news, I heard that people were selling kidneys.”*

Some of the participants became aware through newspapers. Newspaper advertisements were printed to encourage individuals to sell their organ and they highlighted the benefits of sale. Even though kidney sales are illegal in India, and were at the time, newspapers were facilitating communication between sellers and recipients. Abhishek, motivated by the desire to fund his two daughter’s weddings, was connected to a kidney buyer through the newspaper that was shared by a neighbor. In this instance, the neighbor read about the opportunity and Abhishek inquired for more information, while keeping his intentions hidden.

I heard about it from the newspaper. One man was reading [identifier removed] and I came to know from him. I asked him for the address where this was happening. The address was in the newspaper. I asked him to write down the address and give it to me. Then the man asked why do you want this? I said I know him, I think I know him. Then the man wrote the address down and with that address I went.

Despite the open awareness of the opportunity, it remains a secretive practice, as observed in the case of Abhishek. While most people in the community know that this occurs and they learn of it through *“scuttlebutt or market grapevine,”* individuals are careful about sharing their intentions or experiences for fear of law enforcement repercussion or community backlash.

### **Secretive Practice**

Because kidney sales are illegal, PTORs were nervous during the selling process to share information with neighbors and sometimes family members. Interviews indicate that they were afraid of family members attempting to dissuade them from removing the organ and were fearful of punishment if government officials became aware. More information on the role of the family in decision-making will be discussed later in this chapter. While both trafficked persons and non-trafficked persons shared information on the secretive nature of the process, it is the perceived process and consequences by the NPTORs that is particularly interesting because of the connections between understood consequences and TPRO. The process as explained by PTORs is described in Chapter 7, where the individual experiences are delineated. Factors emerged from interviewing NPTORs about their understanding of the organ sale process. These factors include the secretive sharing of information, the observed changes in economic and physical status of individuals, and the role of agents or brokers in facilitating the organ removal. Amit, a 38-year-old fisherman who lives in the same small fishing village as Aanjay and Dipan, both described above, explained from his perspective what occurs when a PTOR has their kidney removed. This process includes a connection with a previously trafficked person, in which the interested individual seeks out information regarding the potential risks. Following this, the potential PTOR is connected to a broker who coordinates the exchange between the seller and the recipient. Amit explained:

Those who have already sold their kidneys tell the others who to go to, so the others who want to sell, go to them. It is a secret channel. The ones who want to sell, ask those who have sold if they are having a problem. The seller would tell them that they have no problem. So the new potential seller asks where to go and who to contact, and thus the chain goes on. They all have done this secretly, but we get to realize that someone is likely to do this. Because they first vanish from the village for a few days.

The entire process takes about six or seven months, and they keep on going away. By the fourth time they stay away from the village, we realize that they are going to sell their kidney.

This perceived process described by Amit is supported by data from additional NPTORs who have either observed parts of this occurring or have heard from others within the community. This description of a “*highly secretive operation*” is also supported by participants who explain that PTORs do not consult with neighbors prior to organ removal. Aanjay, a 60-year-old fish trader, explained this by saying:

The people who want to get money out of selling kidneys will not consult anyone like us. They are very secretive. Once they decide to do this, they will quietly move away from the village and get the kidney extracted and get the money for that. They will not ask, nor listen to anyone.

Study participants also generally described physical or financial changes that were observed in individuals post-transplant. In some instances, individuals who were trafficked for organ removal shared changes in their physical condition with neighbors. In other cases, neighbors were able to notice the changes in physical capacity of the PTORs. Anshu, a 27-year-old housewife and field laborer, described the changes she saw in neighbors:

After she came back, I found out that she had sold the kidney. There was the cyclone after 2 days, then the house broke and fell on her and she was having some pain. That’s how we found out that her kidney had been taken out. I found out she had a lot of money. You can’t make 1 lakh [\$1,460] or 2 lakh [\$2,920] in a week. I’ve been working my whole life and I still don’t have 20 rupees in my hand. That’s how I found out.

Anshu not only became aware of her neighbor’s kidney removal, but was also educated about some of the associated physical consequences, particularly pain related to the organ removal. However, she also became aware of the opportunity to earn a large sum of money quickly, as opposed to “*working her whole life*” for that same amount, as

she described. It is important to consider how individuals in the community perceive the financial and physical changes in individuals post-transplant because data suggest that their understanding and awareness of the consequences of organ removal impacts decision-making.

### **Awareness of Consequences and Benefits**

Study participants all reported varying levels of awareness of the consequences and benefits of kidney removal for compensation. PTORs described how while they knew individuals who had given their kidney for compensation prior, that they did not see any negative changes in those individuals. Data indicate that some of the trafficked persons were unaware of the risks and the consequences. Both their awareness of the opportunity to be compensated for a kidney and their lack of understanding about the costs may have contributed to their decision to have an organ removed. It cannot be assumed that knowing or communicating with a trafficked person can lead to a full understanding of the costs and benefits of the decision. Susmita, a 30-year-old housewife, was acquainted with multiple individuals within the community that did not share any physical health problems post-transplant. Susmita explained that knowing people who did not suffer after the surgery helped give her courage to do it herself.

Those who sold the kidney were telling me that they didn't have any problem, so like them, I wouldn't have any problems. I had the courage to do it, I didn't hear that there would be swelling or any inconvenience or pain. [Name removed]'s father gave but nothing happened to him. Also a man over in my neighborhood gave and nothing happened to him. There are so many people that have given and I never heard any problem.

The initial courage to have a kidney removed was often bolstered by the experiences of others, particularly those who described little to no physical consequences. Like Susmita, other trafficked persons explained how observing the lack of problems

post-transplant gave them the courage to do it themselves. Living in the fishing community, Aanjay was aware of others who had their kidney removed and their successful completion gave him the courage to complete it as well. He explained this simply by saying, *“I saw so many neighbors do this that I found the courage to go for this.”*

A common theme within the study was the awareness of the likelihood of physical problems post-surgery. The only PTOR who had become aware of kidney sales through television, Puja saw the individuals on television in a difficult situation and heard them describe life after kidney removal. Puja explained that her decision-making was based on assuming those on television had positive outcomes after donation. If she had full information, it might have changed her decision. She shared that she *“saw the people on the TV, nothing bad was happening, I was not thinking that something will happen, if I had known I would not have done this.”*

The courage to sell an organ was connected to the belief that if nothing happened to another person who had an organ removed, that nothing would happen to them either. This sentiment was expressed by many of the trafficked individuals who were interviewed. What they learned through their own observations and through the informal village conversations impacted the way that they understood the risk of the operation. Tapas, a 59-year-old fruit seller, like the others described above, believed nothing bad would happen because they did not have knowledge of anything negative happening to others. Tapas explained this by saying, *“I saw other people who had done it and they were ok. Nothing happened to them, nothing would happen to me.”*

Nevertheless, interviews suggest that with the exception of a few individuals, PTORs suffered a host of negative physical, economic, and social consequences. A disconnect existed for many between the expected lack of consequences and the actual consequences. This disconnect can be explained by the trafficked person's hesitation in sharing information due to potential legal and social ramifications. Due to the secretive nature of the practice, PTORs were not comfortable, in many cases, sharing details about an act they regret and feel shamed about with neighbors, though they did share this information with the researcher. It is also the case that the complications that PTORs were experiencing were social and economic and not visible. The individual experiences will be discussed in greater detail in Chapter 7.

Some of the individuals interviewed were aware of the risks of kidney sale. For many NPTORs, knowledge was gained through existing relationships with family members and community members, as well as by observing changes in neighbors. Data indicate that this knowledge likely altered their understanding of the risks and benefits. Knowledge and community awareness may have had an impact on a non-trafficked persons' decision to give an organ. NPTORs shared that they have seen how TPRO affects the individual and the family. On the individual level, study participants reported knowing the associated problems. Vivaan, a 50-year-old fisherman NPTOR, described this knowledge by saying, *"One of the persons who sold his kidney told me of the problems he is having. At least, I am not having those problems."* Just as Anshu described a neighbor's pain after a cyclone within the community exposed this person as a PTOR, Vivaan understood the physical toll of surgery on the body.

A few NPTORs who were interviewed noted how TPRO affected the family, particularly when there was no observed difference in the family's financial status. This observation is aligned with that of PTORs who also described how instead of seeing improvement in their lives, they have experienced further physical and economic strain. Payel, a 35-year-old female who works as a field laborer and makes homemade wine, explained that, *"because of poverty they have sold and now poverty is more, nothing happened in the family, there is no improvement...family is the same, no improvement."* She was keenly aware of how, for some families, there was no improvement in their financial status and therefore, no reduction in their poverty.

The examination of the awareness of consequences and benefits is critical to understanding how knowledge and misinformation spreads within the community and how they impact the occurrence of TPRO. As described by many PTORs, having had the full knowledge of the risks of the surgery would or could have changed the outcome. However, an assessment of the risks was not the only contributing factor, as the economic environment and the need to survive was the main driving force. Trafficked persons explained that if they had known what the physical risks were, they would not have had the surgery. The presence of the economic influences previously described and the additional cultural and societal influences to be discussed do not allow for concrete conclusions as to the role of awareness, as the circumstances for PTORs were complicated and multi-layered. Data do indicate, however, that misinformation among community members impacted understanding. Another key factor in the spread of misinformation regarding the risks of transplant surgery is the presence of brokers within



the community and their role in withholding information and perpetuating misinformation, thus altering understanding.

### **Presence of Brokers in Community**

The themes that have been previously presented in this chapter represent the thematic categories of factors that influence an individual's susceptibility to TPRO. Each of the identified influences can serve as either a protective or risk factor, depending on the circumstance, and the individual. For example, the knowledge of the risks and benefits of kidney removal can allow for an individual to become more or less likely to become a PTOR, depending on their level of knowledge. It is important to explore the mechanisms by which these risk factors make individuals susceptible and result in the trafficking of individuals for the purpose of their organ removal.

As previously discussed, individuals became aware of the opportunity to sell their organ through word of mouth, or through media (newspaper advertisements and television). Upon knowledge of the practice, through a communication channel in the community, interested individuals are generally connected to brokers. Brokers live within the community and serve as liaisons between donors and recipients. Brokers also live outside of the community and frequently visit, as they have a dual role of connecting individuals to work out of state, as well as opportunities for material gain for an organ. Information on brokers is limited due to the hesitance of study participants to discuss their relationship with the broker.

Brokers are motivated to connect individuals with financial problems with wealthy individuals, primarily Indian nationals, either in state or out of state. It is common knowledge that the brokers live and work in this specific community or in

neighboring communities. Three brokers living within the community, or in a close neighboring community, were identified in this study. One of the brokers was a previously trafficked person, who following his own surgery, began to connect others with recipients. To protect the confidentiality of study participants and ensure their continued safety, names and demographic details of the specific individual brokers are being withheld in the reporting of these findings.

Both those trafficked and those not trafficked were knowledgeable and could identify the individuals who facilitate organ sales within the community. Understandably, PTORs were more hesitant to discuss the role of the broker and were fearful of repercussions. During one interview, the participant vehemently denied knowing the broker and took full responsibility for the kidney removal. When asked if a broker facilitated the relationship between himself and the recipient, Aleek, a 45-year-old field laborer exclaimed, *“That is not true. Why should I blame someone unnecessarily? I read about this in the newspapers and decided to get it done.”* Due to the tone of the participant and the context in which the question was asked, the researcher interpreted this as a response based on fear and concern for future repercussions. Although all interviews were conducted in a private space, the existence of the brokers living directly in the community impacted the comfort level of PTORs in sharing sensitive information. Despite this fact, other trafficked individuals did share a little information on how they became connected with a recipient through a broker.

NPTORs were also asked to explain the process in an effort to understand how perceptions agree or differ. Balu, an outspoken 18-year-old male, did not shy away from sharing information on how the process works. Having gathered this knowledge from

friends and family members who are PTOR, Balu suggested that brokers lure potential sellers with money, food, and the promise of financial security.

They either contact the agents. Or the agents mostly contact them, and then they chat them up, luring them with money. Sometimes these agents stay at the homes of [potential] sellers, and they bring them some costly food. They tell them alluring stories about how the seller can become rich.

### **Broker Tactics**

The presence of brokers in the community undoubtedly contributes to an individual's susceptibility to TPRO, as data suggest that brokers use tactics to lure vulnerable individuals to sell their organ. Not only does TPRO occur through word of mouth from one community member to another, but brokers seek out individuals and families to become kidney sellers. Brokers utilize specific tactics to convince individuals, generally those they have selected and targeted, to sell their kidney. The selection of individuals with apparent and known financial struggles is common. For example, brokers have intimate knowledge of the people within the community and they have an awareness of the families who have girl children. They use this information to tempt parents of children who are at or near marriage age. Data indicate that two separate individuals suggested that brokers identify the most vulnerable in the community to encourage and tempt, understanding the factors that are at play, for example the financial stress of having to provide weddings for girl children.

Anshu, a field laborer and housewife who was knowledgeable of a neighbor's efforts to solve her financial problems, explained that she was approached by a broker. This broker attempted to convince her that she could solve her financial problems by giving her kidney. She recalled the interaction:

They said to me: you are poor, your family is so poor, it seems like your family needs money. If you go with me and want to donate your kidney then you can get some money, you can come up. They tempted me. It was a boy broker.

Ultimately Anshu did not have her kidney removed, but her case is not unique.

Other individuals and families have been targeted and approached by brokers within the community. A local community-level social worker, Sonia, is intimately aware of the ways in which brokers interact in the village and the impact of their presence on TPRO. Sonia gained this understanding through work in a part-time job at the local community organization in which she gathered household information from families on trafficking. The targeting process, according to Sonia, is described below.

I told them that if you see strange people in the village, don't talk to them, they will be tempting you to sell a kidney. They might be asking you, they are coming to ask those people, they don't say you have two kidneys, will you sell one? They tempt you in other ways, like trick you. They watch and see which families are poor, with widows, or where so many girls are there. They are poor, there are more people there, 5 or 6 girl children are there and they are getting close to marriage age. Maybe they see that there are boys who are studying. They find families like this and they go to their house. They don't ask if someone will sell a kidney. You don't go and say I want to sell my kidney, they have plans in their mind and they find a family where they can. I tell the mothers that if they see people like this, don't go and sell and don't get mixed up with the broker.

While increasing awareness of TPRO was not her intent at the time, she reported that she later began warning individuals of the dangers of interacting with brokers. The presence of brokers living within the community, and the specific strategies they employ to find interested and desperate individuals, impacts the number of individuals who become PTORs. Not all PTORs were approached by brokers, as they sought out information from neighbors or through media, but the theme of broker targeting emerged within the data.

**Spread of Misinformation.** Beyond luring individuals with promises of wealth, data suggest that brokers purposefully spread incorrect information about the risks of

transplant surgery to potential PTORs. Some study participants explained that they had varying awareness of the physical and economic consequences of kidney removal through information that is shared amongst neighbors within the community. This information, heard and observed as previously explained, could have been partially or totally incorrect, depending on the source of the information. PTORs are hesitant to share information about the physical consequences of surgery, and therefore, community members may be unaware of the risks. Study data suggest that brokers, however, lie to potential sellers to convince them of the safety of the procedure and to secure their cooperation and participation. Believing the word of the broker, Pritik, a 31-year-old male field laborer, aimed to solve his financial problems through selling his kidney. At the time, he was completely unaware of the risks of surgery, having gathered information from the broker who was facilitating the transaction. Pritik, through multiple interactions, built a trusting relationship with the broker and believed that he would indeed have no problems post-transplant.

I went to the broker's house first. I didn't go to his house, but on the way I met him. We discussed it on the road and I took his number and we used to talk on the phone. He used to come to my house and I used to go. He talked with the patient and the patient's family. When they started doing the tests, the broker would come to my house. The broker encouraged it. He said nothing will happen to you, you will be able to do everything and move around and do everything. You won't have any problems. Those who have done it, they are all living. No one has died, nothing will happen to you either.

Pritik's post-transplant experiences, along with other PTORs, are described in greater detail in Chapter 7. It is important to note that data suggest that brokers willingly perpetuated lies and that individuals made decisions based on false information, not understanding the risks they had taken.

In the next chapter, the efficacy of existing TPRO prevention strategies, particularly the role of the state Authorization Committee in approving living donation and preventing organ sales, will be examined. The role of the broker will be further examined in connection to tactics used to circumvent established laws and procedures.

## **Chapter 6. Role of Donor Assessment Process**

### **Donor Assessment Process: Assessment Tools and Broker Tactics**

According to Indian law, potential donors must complete an application and be assessed by a member of the state Authorization Committee (AC) in the capital city. The AC, as discussed in Chapter 2, is a governing board tasked with ensuring that all living donations that occur in the state do not involve compensation. The role of the AC is to determine the motivation of the organ donor and assess the relationship between the donor and the recipient. Indian law requires that the donor be related to the recipient as a parent, sibling, grandparent, or spouse, or in special cases, permission can be granted based on a different relationship. The AC in the state where this study occurred is a board of medical professionals and government officials that is supposed to determine the relationship between the donor and the recipient and ensure that donation is not occurring for socio-economic reasons.

Living donor fitness is determined generally through an assessment of physical, social, and psychological well-being (Duerinckx et al., 2014; Papachristou et al., 2004). The purpose of the assessment is to determine if the potential donor has the physical stamina required to withstand the transplant, post-surgical after-care, and to educate individuals about the risks of surgery, ensuring that they are able to give their full informed consent.

One of the research questions in this study was to examine the factors that protect individuals from susceptibility to trafficking in persons for the removal of organs (TPRO). The AC was created to review each application for living donation in the state and to deny cases in which there is not sufficient evidence to support an established

relationship and should contribute as a protective factor. Denials should be made based on evidence of coercion, manipulation, or a financial transaction between donors and recipients. The role of the AC is also to ensure that the potential donors are fully aware of implications of their decision, including the risks.

All data that are presented in this chapter were collected from study participants, but primarily PTORs. A few NPTORs also provided insight in to the role of brokers in organ facilitation, as they had personally been approached by brokers. As discussed in Chapter 3, permission to interview members of the Authorization Committee, to formally examine the donor assessment process, was not granted, despite repeated communication with committee leadership. No attempt to identify and interview brokers was made. No literature exists on the formalized process in the state, and information on the national living donation transplant procedure is limited (NOTTO, 2014; Shroff, 2009).

**Pre-transplant testing.** All individual PTORs were asked to share their experience with the AC, particularly what was required, what information members of the AC provided, and what they recall as the steps in the process. Some individuals were able to recall less than others; other study participants who had their organ removed more recently, some as recently as three months before interview, could recall more. To gain approval for living donation, each potential donor must be interviewed by the AC panel, provide identification cards, and sign paperwork. Prior to this approval process, individuals undergo a series of medical tests to determine whether they were a biological match with the intended recipient and to assess the physical fitness of the donor. Brokers facilitate this process and accompany potential donors to medical centers, generally outside of the community, in the larger city in where the transplant will occur. Because



transplants occurred for the majority of participants in the larger city, individuals report traveling to the larger city on an overnight train, completing the required medical tests, and then returning the same day. Other individuals underwent tests for months until the broker was able to find a recipient who matched their blood type. Swarna, a 35-year-old field laborer, described the process of medical testing and the way the broker matched him with the recipient.

We went together [referring to broker]. I visited the hospital for over three months and got tests done. In the end, [Name removed] told me that his blood group is A and did not match the one who needed the kidney. But mine had matched, so I could sell my kidney to him. So I got it done.

Like Swarna, some PTORs considered the surgery for a length of time, with one reporting that he considered it for *“maybe about one year, one and a half years. I was thinking about it.”* The length of testing varied among PTORs, with some completing medical tests for months, while others completed the full process in a week. This variation depended on the medical need of recipients at the time and the degree to which potential donors were aware of the urgency. In some cases, pressure from the broker or the recipient’s family impacted the length of time for medical processing and AC approval. Rohan, a 35-year-old fisherman, described that despite his insistence on returning home and considering the decision at home, pressure from the broker did not allow for this consideration. The speed of the process was greatly influenced by the need of the recipient and the broker’s motivation to complete the transplant. Rohan explained:

It happened fast. They were thinking that it should be done fast, though I came back home once. They told me that it was urgent, they were rushing. They told me: “no, you shouldn’t go home,” they were telling me no. After the tests there was some time and I was telling them no, I feel like going back home. They were telling me “no, you don’t go home, some tests are there that you have to do, there is no need to go home.” They were saying that because of the patient, they were doing it fast fast. The people thought that however fast we can do it, that’s how fast we have to do it.

Similarly, Ajay reported that the full medical testing process was completed within two days and immediately his kidney was removed. Ajay, who decided to give his kidney to an ailing employer, described this process as: *“Over two days they checked my body and did a blood test and an XRAY and the full check-up was done. After donating the kidney, I stayed there for 7 days.”* The urgency that Ajay experienced was related to the need of the recipient, in this case, his employer. The length of time to consider the decision to sell a kidney is an important factor in understanding the overall assessment process. Those who completed the full process and screening rapidly had limited ability to fully understand the process and the risks. Individuals should have been informed and data suggests that time did not allow for this informed consent process in many cases.

All PTORs were subject to medical testing pre-transplant, regardless of the timeframe in which they had their kidney removed. While medical tests were often done repeatedly on PTORs, findings suggest that a formalized process for assessing the psychological and social well-being of potential donors did not occur and is not in place. No evidence exists that a psycho-social assessment, discussed in Chapter 2, was done prior to approval for living donation according to international standard (Duerinckx et al., 2014; Papachristou et al., 2004). However, PTORs did indicate that AC members informally questioned their motives and warned of the risk of adverse health effects.

**Approval process.** Information on the actual process is scarcely available in the literature and the information presented was gathered from conversations with study participants and from AC staff, as well as examination of the required application for approval for living transplantation (Appendix E). During the data collection process, the researcher communicated and met with a point person for the AC on numerous occasions

to glean information on the process for approving living donations. Specifically, the researcher was interested in reviewing documents related to assessment procedures. Approval to communicate with members of the AC was initially granted by the chair of the committee, but then rescinded and the researcher was unable to collect any data from this source. The application for approval for living donor transplantation nationally was discovered as a result of independent research and it was not provided by an AC Committee contact persons.

Themes discussed in this section emerged from conversations with PTORs about their experiences gaining approval for kidney removal. Findings suggest that the AC members generally asked why the individual was donating their kidney and warned about the risk of death in place of completing a psycho-social assessment. A purpose of the AC is to determine that individuals are not donating their organ for a socio-economic reason and the process appears to have been developed to gain evidence to make this determination. All potential living donors must appear before the AC, what many PTORs describe as “*court*,” present identification, and provide a family member to co-sign on the organ removal. The AC convenes bi-monthly at a specific location in the city and for each meeting there is a docket of potential living donors. Almost all PTORs recall being escorted to the specific meeting location by a broker and being questioned about their motives. Questions from the AC members included: *Why are you giving your kidney? Are you receiving money for it?* PTORs described receiving a microphone and speaking to a panel of doctors. Many PTORs described doctors asking why the individual was selling their kidney, indicating that AC members are aware that many, if not all of the

potential donors, were likely going to receive compensation. Suparna, a 41-year-old female field laborer, shared:

At [Location removed], the doctors talked to me, they asked me “why are you giving your kidney?” I told them that I have problems at home and I am poor and that is why we are donating. The doctors didn’t say anything, they didn’t tell me what would happen or anything. I went to court at [Location removed], they asked me why I was giving, does your husband know? Why are you giving? I told them that I am donating. They would catch me if I said I am selling, I am giving, however much money they give me then let them give it. They wanted to know how I knew the lady and I told them that my husband was working in their house, that’s how I know her.

Suparna reported being asked about the reason she was giving her kidney and explained that she was aware that kidney sales were illegal and that she must report that she was donating, and not selling. This was a common theme among PTORs; they understood that they must lie about their motivation for kidney removal. Suparna explained: “*The people at [Location removed] were asking me how much money I will get, then I told them that I am not getting any money, I am donating.*” Kiran, a 25-year-old male field laborer, also described this process by saying that “*the doctors there asked me if I was selling or I was donating, I said donating. It won’t happen if you say you are selling.*” Questioning the motivations of the individual and their relationship to the recipient seemed to be the extent of the psycho-social evaluation prior to transplant. Evidence exists that PTORs were aware of how to answer the questions of the Authorization Committee based on coaching they received from the broker. The specific tactics that brokers employed, including coaching, are described in greater detail in this chapter.

Committee members also informed PTORs that the risk of death or physical complications was associated with organ removal, according to the PTORs. Pritik, a 31-year-old field laborer, was warned of the risk of troubles.

They scared me, they were telling me that I will have problems. I will face trouble. I told them what can I do? If he is in danger I have to help him, I want to care for him. I feel pity on him. None of this was true.

Despite the warning from the doctors, Pritik explained that he was indeed donating his kidney out of altruism and not for compensation, understanding that there were risks of potential life-threatening health problems and acknowledging the lie. In a similar situation, Puja, a 35-year-old housewife, was informed by the AC that living donation carries the risk of death.

I also went to court. At the court they told me that since I am giving, then I might die. I said that if I die or if I live, there is no problem. They asked me if I am selling or donating and I told them that I am donating, we cannot say that we are selling. If we say that then we will be caught.

Beyond risk of death and physical health complications during surgery, PTORs were unaware of the additional physical, economic, and social risks of organ donation.

In addition to the interview, potential donors must present identification cards and sign required documents. It is important to note that, as described in the demographic section, PTORs had little to no formal education and many were unable to read. Findings indicate that individuals were unaware of what they were signing, due to their inability to read the documents. Study participants described the paperwork and the process. When asked about the language that the paperwork was in, Puja shared: *“I gave a thumbprint, I have eyes, but we don’t eyes, we have two eyes but we didn’t study, we don’t recognize, those who have eyes will recognize.”* This quote perfectly captures the lack of understanding that PTORs had prior to organ removal, even throughout the assessment process, as individuals were unaware of what was occurring at the time and what they were consenting to. Other individuals expressed a very similar sentiment. For Kiran, a thumb print was also given as consent to a procedure that he did not fully understand.

I signed many papers, with my hand, thumb print. I don't know what language it was in. I didn't study, but I have papers I can show you. They gave me papers. I brought a Xerox of my ration card and of my voter id, a passport size picture, they were in my name.

Unfortunately, Kiran was unable to provide the documentation for review. Some who could read said that documentation was written in English and Hindi, not in their native language. When asked specifically about the consent document language, Tapas, a 59-year-old male fruit seller, explained they were written in "*Hindi, there was also English, some English some Hindi, there was not that much in Hindi, mostly in English, some in Hindi, it wasn't in Bangla.*" Pritik also was required to sign a document that he could not understand at the time. He shared that "*they made me sign many places, it was in Hindi, I didn't study so they were telling me to sign and I put a thumbprint.*" Based on this data, PTORs were unable to provide their consent for surgery based on a lack of understanding due to illiteracy and the language of the documents. No PTORs reported that they were able to read understand the documents they signed. No evidence exists that documentation was read to the PTORs prior to signature.

The approval process for becoming a living donor included medical testing, a formal interview with a panel of AC members, provision of required identification and paperwork, as well as the presence of a family member to co-sign. Preparation of documents and necessary witnesses for this process was completed, in almost all cases, by a broker who facilitated the transaction between the donor and the recipient.

### **Broker Training**

In almost all cases, it was necessary to coach potential PTORs on how to answer committee questions, obtain false documents, and hire false family members for the purpose of co-signing. All of these activities were intended to circumvent the assessment

process and were facilitated by brokers. Without the guidance of brokers, PTORs would not have been successful in receiving approval for their organ removal. Brokers understood the process and guided potential sellers. One tactic that was employed was coaching the potential donor about how to answer the questions of the AC members. When questioned about their motivations, PTORs were strictly instructed to claim that they were donating, not selling their kidney. One identified broker, who himself is a person trafficked for organ removal, was intimately aware of the process, and therefore could prepare potential PTORs for any questions that might arise. Kiran explained the training process:

They taught me how to be clever. They were like you shouldn't say it like this or else you will be caught. The broker teaches you everything that you should say this, what to say. The doctor asked me if I was selling or donating and I told them I was donating. I was selling, but the broker told me not to say that I'm selling, to say that I am donating, so that's what I said to the doctor.

Manas, a 33-year-old male fish seller, also described how he was coached about how to deceive the AC to gain approval for the surgery. Manas shared: *"I had to lie. The broker taught me how to do it, how to lie. He told me tell them that I am donating. I am giving willingly. That's what I said, like this. I told them I knew him [referring to recipient]."* Without coaching, PTORs may have been unable to deceive the AC, and subsequently, their application for organ donation would have been denied. PTORs often required extensive language coaching and preparation prior to application for organ donation. In the case of Pritik, a broker facilitated the full application process. Specifically, he assisted in obtaining false documents, family members, and preparing him for committee questioning. This case was different from all other PTORs because the documents that were provided indicated that he was from a neighboring state, a state in

which a different language is commonly spoken. As part of the training and preparation for the assessment process, he practiced answering questions in Hindi and role-played with the broker.

They didn't take anything. They made some documents for me there. They made a voter ID that said I was from [neighboring state name removed]. I told them that I was from [neighboring state name removed] and that's the card that I had. They were training me there, if they ask where is your village? You have to say my village is this, in Hindi. My house is this. I am from this district. So that's what I said. Every day they were teaching me, this is my village, I am from this district, my house is in [neighboring state name removed]. They were training me for 3 months. They took me to the hospital and I got a check-up and then I took the medicine. They taught me this and kept asking me again and again, I told them everything.

The brokers suspected that the AC would be able to identify the false information, and therefore, Pritik was fully prepared and adopted an alternative persona to gain approval.

Signature and approval from a family member is also required. As discussed in the previous chapter, families of PTORs, if aware of the loved one's decision, were not supportive and aimed to prevent the surgery. Data suggest that brokers were aware of this and utilized both fake identification cards and fake family members to pass the donor assessment process. Participants knew that a family member was required to sign the final paper. To fulfill this requirement, data indicate that brokers hired individuals as stand-in family members. While some PTORs did have their family members present, others were supplied "family members" by brokers. Five PTORs shared that fake family members were used, although likely many more study participants required this, but did not share this during the interview. Without the support of his wife, Kiran required a hired individual to pose as his wife, which was coordinated by a broker.

I got everything done from the broker. They use money and get a duplicate, a false wife. The brokers will get a wife there, they hire someone, that's how they do it. If I don't tell my wife then how will she find out? She found out after.



Aanjay, a 60-year-old fish trader, also described the use of “temporary people” and explained that because he did not have a family member present, that the broker organized a stand-in family member.

I was alone and family members were not there to countersign and sign the bond before operation. Some lady signed as my wife. They [broker/hospital] organized everything. They have temporary people and manage from within.

The inclusion of temporary family members is critical to the overall deception of AC members and subsequent living donation approval. Individuals that do not have the support of their family can overcome this hurdle through broker coordination. In some cases, the “family members” of PTORs differed greatly in their appearance, particularly in skin tone, from the PTORs, indicating a lack of relationship between the two individuals. Despite this fact, AC members did not deny application for organ donation.

### **Inadequate Assessment Process**

The purpose of the assessment process is to identify the cases in which a financial transaction is occurring, but data suggest that the purpose is more to warn potential PTORs, instead of preventing organ sales. Almost all PTORs described being warned of the risk of potential death. An adequate process would include a thorough examination of the social, economic, and psychological factors that impact an individual’s decision to become a living donor. Within this process, the authorizing board should utilize tools to identify red flags that indicate the presence of organ sales, for example the obvious physical differences among “family members,” or the observed difficulties in reading and understanding consent documents. With high rates of illiteracy, the assessment process should include a full verbal explanation to ensure understanding and informed consent.

Where the assessment of living organ donation should serve as a mechanism to stop the sale of kidneys, it often serves the opposite purpose, with ACs approving organ sales. The possibility exists that AC members are not equipped with the proper assessment tools and training, and given access to a tool or process that adheres to international standards for living donor assessment, cases of TPRO can be reduced. Currently the assessment tools that exist do not adequately assess individuals and broker knowledge allows for the use of loopholes. Specific strategies for developing an adequate process with broker loopholes considered are discussed in greater detail in Chapter 8. This study does not address whether or not the members of the AC or the government were aware of these loopholes in the case of the study participants. However, knowledge of the tactics utilized by brokers, if currently unknown, would be a powerful tool in identifying deceptive words and actions within the process.

While there is no evidence that the AC members intentionally support organ sales, the lack of assessment allows many individuals to fall through the cracks. Additional unknown factors, such as payment and coordination with government and hospital officials, could also influence the donor assessment process and the approval of living donation. Interestingly, one research participant suggested that the government is complicit in the approval of kidney sales. While this is only the opinion of one individual, it serves as an example of how the process may not be working and why the process could be flawed. Ananda, a 23-year-old field laborer explains:

Our government knows that people are selling their kidneys and they giving their signature. They are not saying, “don’t sell your kidney, we will solve your problem.” They are not saying this, instead of saying that they are giving [their] signature and allowing. This is their fault, why can’t the government prevent this? Government should say and should do something. They know it is happening, but there are still putting their signature and allowing it. Knowingly they are putting the signature, why?

They are getting the money, no one will give the signature or their permission without the money.

The intentions and actions of the AC were not explicitly examined in this study, however the experiences and opinions of study participants are important to examine within the larger context of how TPRO occurs within the state.

The established living donor assessment process is intended to assess potential donor motivation and ensure that individuals are not removing their organs for socio-economic reasons. The process included medical testing, a superficial assessment of potential donor motivation, a warning regarding the risk of death, required submission of paperwork, and a witness for final signature. Data suggests that brokers assisted PTORs in obtaining approval for organ donation through the use of coaching, falsified documents, and “stand-in” family members.

## Chapter 7. Individual Experiences

The themes that have been previously presented represent the economic, cultural, and societal influences that emerged from the data, as well as the role of the donor assessment process. In this chapter, the individual experiences of persons trafficked for an organ removal will be presented. While each individual had unique experiences and feelings with regard to their organ removal, patterns did emerge with regard to their feelings the day of the surgery and the consequences that individuals experienced post-transplant.

### Experiences Day of Transplant

**Feelings of uncertainty and fear.** All individual PTORs were asked to recall their feelings the day of the surgery. Depending on the time since transplant, some were able to recall more than others, however, all expressed that they remembered what they felt that exact day. Almost all PTORs described a feeling of uncertainty, whether it was related to their health status post-transplant, or resulting from a lack of knowledge of what would occur that day. General fear was commonly described by PTORs. Tapas, a 59-year-old fruit seller, despite having had his kidney removed many years before, was able to recall his feeling at the time: *“I was afraid, everybody will have one fear, in something.”* This fear was a result of many being unaware of the details of the procedure the day of surgery. Not knowing if she would live after the surgery, Prisha, a 35-year-old housewife, had a desire to explore the larger city where the surgery occurred. She shared: *“When I went to [city name removed] I wanted to go around and see the place. I went around and around. I thought I might die from the operation, so I went to see everything before the operation.”* At the time, she was extremely uncertain about her future, and as a

result, did not want to die without seeing the city. PTORs commonly expressed that they were completely unsure of how the transplant would be performed. Puja, a 35-year-old field laborer, was only aware of the time she was required to arrive at the hospital.

They didn't tell me what time the operation would be, they only said to me that I have to be here by this certain time. I was waiting for it and right before the operation they told me to go inside to the hospital room. They gave me one injection in my back, I don't know how long the operation took. I think that for four hours they kept me in the operation room. Once we come back to normal life then we can come out. We stay in that room until we come back to normal life.

Prisha, like Puja, was not informed of the procedures and this caused anxiety and uncertainty. Prisha explained:

The doctors didn't tell me what was going to happen. The hospital workers said, "don't move, don't move too much, it will be painful." They said that it would be painful, but that I shouldn't move. They told me to be patient and hold on and wait. This is all they said to me. I was asleep when they were cutting, but I knew they were cutting. I closed my eyes and then I knew that they had cut. I understood when they were cutting, but I couldn't open my eyes. I was just worried about my kids, they were at home. I was worried about them. They put me in the operation room and they brought some instruments. The nurses were asking me, "how many children do you have? How old are they?" They put something in my mouth and I started feeling like my body was dying. Three of them took me to another room and then I knew, my eyes were open.

Prisha became aware of the procedures in the moment and was worried about the future of her children, unsure if she would survive the surgery. Feelings of uncertainty and fear led some PTORs to consider leaving the hospital the day of the surgery.

**Desire to leave hospital.** Prompted by fear of the unknown, some PTORs said that they considered leaving the hospital on the day of the surgery and changing their mind about the surgery. Pritik, a 31-year-old field laborer, explained how his fear made him want to leave.

I was feeling a little scared. I was already inside and there is no way to run away from there. There was no way to run. I couldn't find the way or I could have run away. I

saw so many people being kept flat. I saw them and I was scared. Once they take you inside you can't come out. Some madams were there, they were doing everything.

Similar to Pritik, Kiran, a 25-year-old field laborer, was also frightened and considered leaving the hospital, if it were possible at the time.

I was thinking that if there was a way to get out I could run away from there. If the window was broken, I would never come back. I was so frightened, but I got the courage and I knew there was no way to run away. If I could have run away, but I knew if I ran away that I wouldn't get the money. I was doing it for the money.

For Kiran, it was necessary to exit through a window, because the presence of guards made it impossible for him to make a choice to leave.

If the hospital workers would have told me this would have happened, I could have gone and never gone for this. Once you go inside, you cannot come out, a guard is there. For those selling kidneys, they have security guards so that we can't run away. If they could have explained it to me, then I could have gone home. Donors shouldn't run away so they put a guard.

Kiran was both unaware of what would occur and felt unable to leave the situation and change his mind once he arrived at the hospital. Despite their desire to “*run away*,” neither Pritik nor Kiran left the hospital before the surgery. Both felt they were unable to leave once they entered the hospital, and Kiran reflected on the sole purpose for the surgery. Knowing that he would not receive the money, he felt compelled to stay and complete the transplant. Most PTORs dealt with uncertainty the day of the transplant not by attempting to leave, but rather by leaning on their own faith to survive the surgery.

**Faith in God.** Individuals were asked to recall their thoughts in the moments leading up to the transplant. Overwhelmingly, PTORs described how they placed their lives in the hands of God through prayer, regardless of religion. They described their fear of death, but also their certainty that if death occurs, it will be the will of God and that their children will be protected. Kiran explained that life is given by God and also taken

by God and that his fate is decided this way, that God is in control of his life. He explained:

Dying or alive, everything is God only. If Allah is telling me that I will live, if he has written, then I will live. If he has written that I will die, then I will die. If I am alive, then I will come back, if I die then I die.

Similarly, Babu, a 32-year-old male field laborer, accepted that God was in control of the situation, although he remained unsure. Babu shared: *“I called God, but whatever will happen will happen. What will happen to me?”*

Faith extended beyond protecting the individual PTOR during the surgery to include prayers to protect children. Prisha described how she paid respect to a statue of Ganesh, a Hindu deity, and prayed that God *“look after”* her children.

They took me upstairs by elevator. I saw a Ganesh idol in the elevator, it was the fourth or fifth floor, I don't know, but I saw a Ganesh. I saw it in my mind and I greeted [note- with palms together, she lifted her hands from forehead to mouth to demonstrate, in a traditional form of respectful salutation] and said, “God if I die please keep all my children in your hands. You have to look after them. I was just able to see a little, my eyes didn't completely close so I saw it. I remember seeing this and thinking this. I said “God I am dying, I'm going to you but I'm keeping my three children in your hands.” I don't know what happened to me after that. After I realized they had cut me.

Fully unaware of whether she would live or die, Prisha described placing her fate in God's hands. Feeling unable to make an alternative choice, Prisha was resigned to her certain fate, which she understood as death. Religion helped Prisha, as well as other PTORs, come to terms with what must occur for survival, the removal of their kidney. Faith in God gave many PTORs strength to proceed, despite fear of death or an unknown future.

**Feelings of loneliness.** Study participants expressed that upon waking up, they experienced feelings of loneliness and sadness, as their family members were not present

and did not accompany them to the hospital. Not uncommon for PTORs, Puja, a 35-year-old field laborer, traveled to the larger city without her family to complete the transplant. She explained, *“I went there alone, my husband didn’t go. I went and laid down in the bed and no one was there by the side of the bed.”* Puja experienced feelings of loneliness, as she was acutely aware of her lack of visitors. Feelings of loneliness were coupled with feelings of sadness for Pritik. A long distance from his home and his family, Pritik described becoming emotional after surgery.

I was thinking about why I gave. I was feeling so tired at that time. I wanted to sit, but you cannot sit, it was not possible to sit down. I was in one bed and you can’t sit. I was crying. I saw that no one was there, no one was coming to see me. I’m not near my house, my family can’t come see me, they don’t know I’m here. The nurses here are my only family, parents, everything. The nurses were saying, “why are you crying? Don’t cry, you came by yourself.” They were taking care of me.

Beyond experiences on the day of the surgery, PTORs expressed how organ removal changed their life and the consequences they have faced as a result.

### **Consequences**

**Physical consequences.** The most common physical consequences reported by PTORs were pain, overall and at incision site, weakness, fatigue, change in ability to lift heavy items, and loss of physical functioning. Data indicate that many of these symptoms can be attributed to a lack of post-surgery after-care. While the transplants occurred in accredited hospitals and were performed by skilled medical professionals, almost no PTORs received any follow-up medical services. The average stay in the hospital post-transplant was short and PTORs did not have access to follow-up care once they returned to their community. A lack of surgical after-care could lead to infection at the incision, which results in swelling and pain. Ashok, a 33-year-old fisherman, experienced a multitude of physical complications. He described how side pains limited his ability to



bend or lift weight by saying, “*There are pains inside* [note-indicating the side from which the kidney was extracted]. *I cannot bend down for too long or lift any weight. I do not have the courage or confidence to lift a weight of say 20 kgs [44 lbs].*” Ashok’s work as a fisherman required him to be able to lift a large amount of weight and he reported that the surgery has affected his confidence. Puja, a 35-year-old female field labourer, also described changes in her confidence level based on changes in her health status. She explained that: “*After selling, I cannot work outside. I am frightened, what will happen to me? I used to plant paddy and uproot the grass from the field but I’m frightened. My physical health is not that good.*”

PTORs also commonly explained that they suffered from general weakness due to the removal of their organ. The full impact of major surgery on the body was conveyed, as “*our full body is affected when you give one kidney, your full body is feeling weak*” (Kiran, 25-year-old field laborer). Prisha, described the changes in her body by saying, “*More than before, I am weak now, my strength is down. I have pain sometimes, back pain. I can’t work in the sun, if I’m in the sun then there is pressure.*” Due to the type of work available in the community, a loss of physical functioning directly results in an inability to earn an income.

**Economic consequences.** PTORs commonly stated that they “*cannot work as much*” and the changes in their physical ability translated to changes in economic status. Despite receiving payment for their kidney, most PTORs no longer possessed the money, having spent it on an acute stressor, such as a daughter’s wedding, or to care for their family’s health and well-being.

Manas, a 33-year-old fisherman sold his kidney because of an urgent need to earn

money for his family. His *“father’s cancer had to be treated”* and he sought a broker who could loan him the money quickly in exchange for his kidney to be removed at a later date, once a suitable recipient was found. Manas’ father was suffering from stomach cancer at the time and Manas described that his options were limited and he *“didn’t have any choice. We didn’t have any land and nothing was there. My father had cancer, stomach cancer, we needed so much money so I borrowed it from the broker.”* His father received the operation, but unfortunately did not recover from his illness. On the exact same day that Manas was scheduled to have his kidney removed to repay his debts to the broker, his father passed away. All of the money that was received in exchange for his kidney was used to pay for his father’s medical treatment and funeral services. Manas explained that: *“Not all of it was spent on my father’s treatment. The rest of it was spent on the post cremation ceremony for my father, so it was spent on that.”* Manas’ financial situation post-transplant did not improve, as the entire amount was spent on his father. He explained he has experienced physical complications, such as his *“stomach bulging out like a balloon”* and this impacted his ability to improve his economic situation.

Once the sum received from organ removal was spent, most PTORs were unable to earn at the rate they once earned due to physical complications. As a field laborer, Aleek, depended on his body to earn a daily wage. A full day of work for Aleek was reduced to a maximum of two hours of hard labor at one time, thus limiting the amount he could earn. He explained:

I cannot work as much. I have become very weak. I can barely work for two hours at a stretch. Then I have to rest for a while and then again start working, so I am suffering. Suddenly a part of the stomach swells out like a balloon. It is very painful. I have to suppress my breath for a few minutes for the pain to subside.

Ashok also described a reduction in hours which translated directly to a reduction

in income, comparing his physical ability pre and post-transplant. *“Earlier, I used to work from 8 in the morning till 4 pm, with a short lunch break. But now I can work only from 8 am till noon, at the most, and have to return home after that.”*

**Emotional consequences.** Some PTORs described emotional consequences as a result of organ removal which included fear, shame, and isolation from family members and the community. They experienced fear of repercussions from family members, who may abandon the individual for their choice to remove their kidney, or from potential incarceration or interaction with law enforcement. Tension within the family post-transplant was due to either the PTORs’ inability to work or the fear of their future inability to work. Suparna, a 41-year-old field laborer, was able to continue working, but feared what might occur if her strength lessened. She was afraid that she would be discarded by her family for her decision to sell her kidney.

I am frightened that my daughter-in-law or my sons also know that I sold. Now I can work, but if I can’t work, will they look after me? How will I live? Who will look after me? [Note- she was crying, wiping her tears with the edge of her sari]

Suparna’s family, like those of other PTORs interviewed, did not approve of her organ removal. Suparna feared that she would be blamed in the future if she was unable to work and contribute to the family and she would be ignored and abandoned as a result. For others, including Pritik, a 31-year-old field laborer, emotional consequences resulting from family member reactions were experienced directly following transplant. Pritik described his family’s immediate reaction to the knowledge that he had removed his kidney.

They scolded me and beat me, but what was I going to do? I had made a mistake, I can’t get it back. My uncle, my mother, they all scolded me, I did it and I can’t get it back, it’s gone. You can’t get things that are gone back.

Some individuals experienced isolation as an emotional consequence of organ removal. Puja, a 35-year-old field laborer, had a heightened fear of law enforcement and she was often afraid to leave her home. She shared, *“After selling the kidney, we were both frightened that they will come and get us and take us to jail, put us in the jail, so we were not coming out.”* This fear paralyzed Puja and kept her isolated within her home, fearing questioning from police or community members. Her fear even impacted her desire to seek services *“at the mission”*, the local organization that provides medical and educational services.

We were afraid to come out of our house after selling the kidney, what will people say? What will the police ask? We came to the mission, but we did not enter inside the gate. We were outside the boundary, we didn’t have courage to come in.

Eventually Puja overcame her fear of entering the mission, however, even at the time of the interview, she remained concerned that she would be exposed and incarcerated. For her, fear was a long-lasting emotional consequence of organ removal. While evidence does not exist that individual PTORs in this specific community have been prosecuted by the government, Puja was likely fearful based on past journalists who visited the community and drew attention to the trafficked persons. Perceived corruption between the media and the government may have exacerbated her fear of repercussion. General mistrust in the government may also have impacted her trust in the systems that exist to protect individuals. An additional emotional consequence that was expressed by nearly all PTORs was the feeling of regret.

## **Regret**

All PTORs interviewed were asked to describe their opinion of kidney selling and how they felt about their organ removal. With the exception of two individuals, PTORs

described regret that was a result of general disappointment, negative changes in health status, lack of substantial positive economic change, or a combination of reasons.

Overall, PTORs described “*feeling so sick,*” questioning “*why did I give?,*” and reporting “*suffering, feeling so sad.*” Experiencing life post-transplant, many PTORs described how the changes in their body led them to regret their kidney removal. Suparna’s health was negatively affected and she described her feelings by sharing, “*I feel like I made a mistake. In order to become healthy, I need healthy food, then my health will be ok and my body will be ok, but my body is not ok. I am regretting a lot.*”

Not only did the loss of good health impact feelings of regret, but the loss of the part of the body and the inability to give that part of the body to another caused regret and disappointment. Prisha, a 35-year-old housewife, commented on the limits of her body and the impact of losing a piece of herself.

I was regretting instantly, part of my body is gone. I lost this, why is this gone now? I was crying. Now I cannot give it to anyone else, if my husband needs it or my children need it, I would have to search for one now. I cannot give to them anymore.

As mentioned previously, PTORs did not experience a marked positive change in financial status post-transplant. This fact was tied to feelings of regret, as individuals processed the risk and return of the surgery. Following surgery, upon processing the sale and the financial benefit received, Ananda, a 23-year-old field laborer, understood that it was a “*mistake,*” as it was possible for him to earn a livable working out of state. Ananda shared:

I got just Rs 200,000 [\$3,134]. That is a small amount, because now when I think of it, I realize that if one works hard it is not too difficult to earn Rs 200,000 [\$3,134]. If we work in Delhi it is easy to earn Rs 10,000 [\$156] to 15,000 [\$235] a month. So now sometimes I think it has been a very serious mistake selling the kidney.

For Ananda, the amount received was not worth the loss of his kidney and this resulted in feelings of regret.

Giving the gift of life remained a source of pride for one individual, as his motivation was both financial and altruistic, but primarily altruistic. Ajay, a 21-year-old male introduced in Chapter 4, developed a brother-sister relationship with a member of his employer's family and chose to remove his kidney to save her life. Ajay was interviewed a year and a half post-transplant and he remained firm in his decision to give his kidney to his "*sister*." Despite reports of changes in health status, "*before my health was okay, but now I have no strength and half of my strength is gone*," Ajay continued to be proud of the impact that he made on the life of another person and did not express regret. He shared this sentiment by saying, "*I am not thinking now that my life is destroyed. I have done great things. Because of me one person is living, if I am in trouble then I will manage somehow. I saved someone's life. No one forced me.*"

Devoid of altruistic motivations initially, one PTOR cited his satisfaction in receiving payment for his kidney as the reason he did not regret selling his kidney. His motivation was purely financial and receiving payment justified his decision. Tapas, a 59-year-old fruit seller, who sold his kidney many years prior, recalled feeling happy post-transplant. He shared that, "*There was nothing to feel sad about, I happily came back home, the day I got out of the hospital, the person gave me Rs. 5,000 [\$78].*" While he described difficulties that he had experienced in the interview, he never mentioned specifically that he regretted his decision. Having reflected on his decision, Tapas explained that he was also pleased that he improved the life of someone else, saying: "*I gave it and I am also okay, someone is living with my [kidney], it is good.*" Both Ajay

and Tapas described feelings of satisfaction, both having saved another's life, and one having provided for his family and leaving the hospital at the time unscathed.

Data suggest that the lack of regret among PTORs is very rare. While Ajay and Tapas remained proud, one individual who was once proud, later felt regret. For Misha, a 45-year-old housewife, feelings of pride were replaced with feelings of sadness and regret over time. Misha explained: "*At that time we were proud that we gave life, but now we feel sad, we don't know why we went to give like this, regretting this.*" While not explicitly stated, it can be assumed that her change in perspective was due to changes in her health, as she is now "*not able to do any work*" and describes herself as "*sick.*"

Individuals who had their kidney removed had a range of feelings the day of the transplant, but primarily felt uncertain, anxious, and alone. Faith played a large role in their ability to cope with the unknowns and stress of the surgery. Post-transplant they experienced physical, economic, and emotional consequences, which led the vast majority of PTORs to regret their organ removal.

## **Chapter 8. Discussion**

### **Summary of Findings**

The purpose of this study was to identify influences that contribute to susceptibility to trafficking in persons for the removal of organs (TPRO). Specifically, the research questions addressed were:

- What are the life circumstances or factors that make individuals vulnerable to being recruited to sell an organ?
- What factors protect individuals from having an organ removed for compensation?
- Does the living donor assessment process serve as a mechanism to protect individuals from kidney sales?

To answer the research questions, qualitative analysis of themes that emerged from interviews were presented in Chapters 4-7. Themes were developed through an iterative grounded theory process which included interviewing study participants, revisions to interview guides based on participant responses, and distinct levels of coding and comparing data. In answer to the first two research questions regarding the factors that either made an individual vulnerable to TPRO or protected them, influences at all levels both encouraged and discouraged TPRO. In an effort to understand how these factors contribute, a brief summary of the findings is presented.

### **Vulnerability and Protective Influences**

While this study explored both vulnerability and protection in two separate research questions, it is difficult to separate the discussion of influences with regard to TPRO, as the presence or absence of a particular influence could be both positive and



negative. For example, the role of family, depending on the level of involvement of the family, and the knowledge of the family members pre-transplant, could impact the family member's status as a trafficked person by discouraging them from donation. In many cases, study participants described how the involvement of their family either influenced their decision-making (i.e. use of family pact), or did not (i.e. family was unaware of the member's plan to remove the kidney). In all cases, the role of family was a critical influence, either as a presence or an absence. To fully understand how influences combined and impacted vulnerability, they are discussed together.

**Economic influences.** Access to resources is likely the most critical factor to examine when trying to understand how individuals became PTORs. Access to resources in this community is limited for many individuals, but especially so for those who became trafficked persons. It was this lack of resources, coupled with other factors, which will be discussed later in this chapter, which made the individual vulnerable. Kidney sales offer individuals an alternative way to earn income. Participation in government work schemes was not a solution to economic problems for any study participants, regardless of trafficking status. Both the lack of government work and funding to compensate individuals for their work negatively impacted individuals in the community, and in some cases, contributed to susceptibility to trafficking.

Individuals who have access to resources may be more protected from becoming trafficked persons, particularly those who own land. Both land ownership and connections to borrowing and saving organizations are protective factors. They allow individuals to get capital on a regular basis or during an emergency situation. There are many foreseeable expenses that will arise over the course of a lifetime. For example, for

those with girl children, it can be predicted that money will be necessary for the wedding of their daughter. Connection to a borrowing or saving organization over the course of time enables the individual to procure funds over time to prepare for a large life event. Families who suffer emergencies, such as a sudden illness of a family member, may need access to large sums of resources immediately. Borrowing and saving organizations in the community currently offer small loans, some may cover the costs of a sudden medical illness, depending on the illness, and some may not. The reach of these organizations is limited and the amount available is often insufficient. Families generally need to prove a form of collateral, such as livestock or a suitable home, to receive the loan. Women can become involved in working empowerment groups, but the shared nature of the group does not allow for individual women to get a large proportion of the group's funds. For those who do not have the collateral or own land, kidney sales provide individuals with a large sum of money to respond to an emergency situation. It is the emergency situations and planned events that also influence decision-making, as they arise within the constrained economic environment. The stress of having a sick and ailing loved one and no avenue to help this loved one is difficult and painful. In these situations, individuals seek any type of solution to solve their problem.

It is not only the emergency situations and the planned events that individuals need capital for, but also just for daily living. Some PTORs reported hunger and starvation as a primary motivating factor in their kidney sale. The lack of both resources and access to resources impacts the individual decision-making process with regards to TPRO. It can be understood that those who did not have resources were more likely to become PTORs.

Findings suggest differences exist in the worldview of PTORs and NPTORs with regard to the use of their body for economic gain. A theme that emerged within the study was the conflicting views that both trafficked and non-trafficked individuals had regarding the utility of their body. Many PTORs described the use of his/her body to improve their financial status through the sale of a kidney. Conversely, NPTORs expressed that they utilize their body differently, through hard labor, as a means of income generation and poverty reduction. This viewpoint is in contrast with PTORs who described how lack of choice and desperation led to their organ removal, as their financial situations were dire. It is important to note, however, that NPTORs may have possessed additional resources, such as land, which allowed for the freedom to address financial problems using alternate means.

**Cultural and social influences.** The cultural and societal influences presented in Chapter 5 include gender, the role of the family, and the spread of information within the community. Gender and work availability for women was a vulnerability factor for a group of the study participants. All PTORs that are women and that were interviewed indicated that gender played a role in their decision. Opportunities for women to earn income in the community are extremely limited. Women are expected to stay in the home and care for dependents, and it is difficult for women to earn an income outside of the home. It is this fact that influences a woman's feelings about her ability to contribute to the household. Women expressed their daily activities and described how they "*sit all day long*" as a way to explain why they sold their organs. The description of sitting all day long at home can be interpreted in two ways. First, the women are describing how they are limited in their scope of work and how they are at home, not earning what their

husbands are earning. Secondly, if the women face physical consequences as a result of transplant, these consequences would be less detrimental and impact them less than their husband, who must do hard labor to earn for the family. The lack of opportunities for women to earn an income makes them more susceptible to TPRO, as other possibilities for income generation are limited.

As described previously, the family has an influence on the decision-making process regarding organ sales. The findings indicated that for some of the NPTORs, a family-level decision had been made to never allow a member of the family to sell an organ. Not all families make a pact, but often families of PTORs expressed their discontent about their relative selling an organ. In some cases, family members pleaded with their loved one and tried to prevent them, but had a failed attempt. Family decision-making was critical in some cases, particularly non-trafficking cases, but in others, families were unable to fully influence their relative. The fundamental observed difference in some cases was the stated family decision. In other instances, however, family members were unaware at the time of a loved one's decision to remove his/her organ, eliminating the role that the family member could play in prevention. Whether family members were involved in decision-making impacted whether the individual pursued organ removal.

Findings indicate that family presence is a critical factor. In some cases, PTORs were encouraged by brokers to rapidly make a decision to remove their kidney, leaving little time for thought or consultation with family members. For two PTORs, the individuals were working out of state when approached by brokers to sell their kidney. These individuals were unable to communicate with family prior to organ removal.

Donors that are removed from their family are more vulnerable and may make decisions, under pressure, that they otherwise would not. Brokers are able to exploit this vulnerable time when individuals are removed from their family. In some instances, the family was not aware of the kidney sale until after the individual returned to the village.

Following kidney removal, regardless of family knowledge prior, the individual returns to the community and others become aware of their trafficking status. Families who were previously unaware, families who were aware, and community members all begin to formulate opinions on the risks and benefits of kidney sales, based on what they seen and heard. Community awareness in this study can also serve as a vulnerability or protective influence. Interaction with individual PTORs impacted understanding of the consequences of organ sales. When individuals see and hear PTORs expressing negative physical, economic, or social consequences, this may shape their understanding.

**Donor assessment process.** Based on findings, the donor assessment process, intended to serve as a protective factor, is not protecting individuals against TPRO. The process for assessing potential living organ donors, as discussed in Chapter 6, includes medical testing, a perfunctory assessment of donor motivation, submission of identification and paperwork, and the inclusion of the signature of a family member. The process of assessment was generally facilitated by a broker who serves as a liaison between the potential donor and the organ recipient. Having extensive experience with the process, often due to their own status as a kidney seller, brokers can manipulate the system. Based on interviews with PTORs, brokers are well versed in the process and use this knowledge to their advantage with tactics intended to help potential donors pass the donor assessment interview. Brokers also collect the necessary documentation and supply

necessary “family members” (i.e. when potential donors do not have the support of their own family members. The actual formalized process, as described by PTORs does not meet standards for a physical and psychosocial assessment that is internationally recognized as a model standard for living donation assessment.

**Individual experiences.** PTORs shared their individual stories of what they experienced both the day of the transplant and post-surgery. Memories of anxiety, fear, and uncertainty were commonly expressed among trafficked individuals, especially as they recalled their lack of knowledge of the intended process the day of the surgery. Findings suggest that some individuals wanted to leave the hospital before surgery out of fear, but they were fearful of repercussions and could not repay pre-transplant funds they had received from the organ recipient. None of the individuals who described their desire to “*run away*” from the hospital were successful because of physical constraints (i.e. windows) and the presence of guards whom they assumed were affiliated with either the hospital or the broker.

Others described that they used prayer to deal with fear by “*placing their fate in the hands of God.*” A coping mechanism that was described by almost all PTORs was the use of prayer and placing their fate in the hands of God. PTORs described the importance of religion in the moments leading up to the surgery and immediately following their return “*back to life*” or when they regained consciousness.

Physical, economic, and emotional consequences post-transplant were described by almost all PTOR study participants. The most common physical consequences were pain at the extraction site, fatigue, and general reduction in ability to work. This inability to work, in turn, impacted the economic status of the individuals and their families. The

economic status of the PTORs did not improve as a result of organ removal; participants attributed this to their inability to earn at the same rate post-transplant as they could pre-transplant. The decision to remove an organ was made due to dire financial need at the time since their economic well-being was already compromised.

Fewer PTORs described emotional consequences related to their organ removal. The ones who experienced emotional consequences mentioned the impact of surgery on their lack of confidence, such as when an individual found himself unable to lift large amounts of weight as required by his agricultural work. There was also fear of law enforcement backlash. PTORs described fear of leaving their home and engaging with the community concerned that community members would be aware of their trafficking status or they would face legal repercussions.

Directly linked to the described consequences was an overwhelming feeling of regret, even though this was not held by all PTORs. Some individuals described regret immediately following surgery, while others felt regret after having struggled with physical, economic, and emotional consequences. Interestingly, two individuals did not regret the organ removal. These “outlier” cases are critical to understanding how donor motivation is different for them than the others. For most participants organ removal is primarily for financial purposes, but for others, individuals are motivated by altruism. The one PTOR who did not feel regret held the desire to help another and felt his decision was good as he now had a role in saving the life of another individual. The other PTOR who did not regret his decision felt satisfaction once he received payment for his organ, as opposed to any moral satisfaction. This differed from the perspectives of the

rest of the PTORs who expressed that even payment did not lead to satisfaction and that they continued to regret having the organ removed.

### **Theoretical Framework Re-Examined**

In Chapter 2, Unitary Assumption Theory, Disaster Vulnerability Theory, and the theoretical concept of Abuse of a Position of Vulnerability were summarized and examined for their applicability in understanding study data. Unitary Assumption Theory posits that decisions are made rationally and for the benefit of the household. This theory neglects to address the socio-economic context in which individuals are making decisions. For example, one PTOR who expressed that she was forced by her husband to have her organ removed for his own personal material gain did not make a rational decision for the benefit of the full household. The unitary assumption model has not been previously used to explain human organ sales. The complexities of the problem require that the contexts in which decisions are being made to be considered. Viewing TPRO solely as an individual decision only neglects to address the forces and factors that influence the decision. PTORs' choices and options were described as non-existent. Choice in its definition requires more than one option, or at least two possibilities. When faced with no options but to sell a kidney, the individuals are not acting within a choice framework.

Vulnerability in the context of trafficking is defined as the psychosocial, contextual, and environmental conditions that increase susceptibility to trafficking, such as poverty, gender, and minority group status (UNODC, 2013). Not only are specific individuals and communities more susceptible as a result of these conditions, but the abuse of the person's position of vulnerability (i.e. these conditions) is the means by



which the abuse occurs (UNODC, 2013). In situations where there is no other understood alternative to organ sales and the individual may have felt that there was “*no other choice*,” the decision may have been greatly influenced by external factors.

### **Poverty Originated Organ Removal (POOR)**

Although Unitary Assumption Theory, Disaster Vulnerability Theory, and the concept of Abuse of Position of Vulnerability can be useful in understanding parts of how organ sales occur in this specific community, none of the theoretical concepts fully explain the mechanism by which individuals are susceptible to, or protected from, TPRO.

The purpose of grounded theory methodology is to develop a theory that is rooted in the data, that emerges from an iterative process of data collection, data analysis, and comparison. Based on study data and the themes previously presented, the concept of Poverty Originated Organ Removal (POOR) is introduced. POOR is a theoretical contribution to the overall conceptual understanding of TPRO, but is particularly relevant to the context in which study data was collected.

In this study, the whole population is vulnerable, but specific influences make individuals particularly vulnerable, while other influences protect individuals. The way in which vulnerability is expressed or characterized for the individual impacts their trafficking status.

As previously described, study participants, both trafficked and non-trafficked individuals, utilized their bodies in the way that they could at the time to survive or meet financial obligations. Individuals had to either sell a part of their body or to depend on the physical labor of their body to ensure survival. Nearly all NPTOR study participants stated that they survived by their “*own self alone*,” meaning that their physical capacity to

work determined their health, well-being, and ability to support their family. PTORs did not view their physical capacity to work as sufficient, and they utilized their body in a different way, thus becoming trafficked persons as a result of their poverty. The use of the body in both instances is due to the overall poverty within the community. The economic environment in which the study participants live limits the ability to earn income to survive; the options for intellectual work or other non-physical labor work are limited. This is due in part to a lack of education within the community; study participants were illiterate and did not complete primary school. The lack of available work in the community also impacted an individual's ability to earn an income outside of the agricultural sector. It is nearly impossible for study participants to earn a stable income in a non-agricultural job unless they travel to another state. Out of state positions are considered more stable because they are not often as dependent on the agricultural season, but they are also usually physical in nature and require strenuous use of the body. The fact that participants must use their body, in one of the two described ways, is a marker of the overall poverty within the community. The poverty experienced by the individual within the community is what ultimately impacts his/her status as a trafficked person. All of the influences identified in this study are related to the amount of resources that an individual possesses, or their perception of how their resources can protect them in the case of an emergency.

The financial fragility of individuals, particularly at times when they know that their income is not sufficient for daily life or planned events, for example the wedding of a daughter, is exploited by brokers who understand the degree to which people are impoverished. Data indicates that brokers are aware of the overall lack of resources

within the community, as some of them originated from the same community and are trafficked persons who now facilitate organ transplants between desperate recipients and impoverished sellers. One can speculate, however, that previously trafficked individuals are working as brokers to earn a stable living, as their own organ removal has limited their ability to participate in the workforce due to surgical complications and generalized weakening described by other PTORs. It can be argued that had the brokers earned a stable income prior to their own transplant, they may have never had an organ removed and thus become brokers.

Although brokers were not interviewed, study participants described brokers as being from the community and embedded in the community, thus allowing them to identify particularly vulnerable individuals and offer them a solution to their poverty. In this community, TPRO occurs due to persistent and widespread poverty and the perceived ability of brokers to provide a solution to individuals who have no other choice.

Individuals do not have alternative choices in part because of the lack of adequate government poverty reduction programming. National programs to provide a social safety net are not successful, despite their existence. The lack of government response to poverty, particularly in this rural agricultural community, has been linked to TPRO in this study. The desperation that was experienced by PTORs could have been reduced or eliminated with financial support and a guarantee of a basic living wage. Existing prevention programs and policies must be re-examined and revised with the goal of overall poverty reduction, aiming at ending organ sales based on economic reasons. Along with poverty reduction, the donor assessment process that is intended to prevent

organ removal for socio-economic reasons is not effective. To protect individuals from TPRO, the government must ensure that poverty reduction policies are effectively implemented and that donor assessment processes work and allow options to divert desperate individuals to other forms of income.

The protective influences that were identified in this study are critical to understanding how poverty originated organ removal (POOR) occurs. Almost all study participants that were interviewed are living in poverty, but some possessed additional resources, whether material or knowledge-based, that protected them from TPRO.

In these cases, it was not whether an individual was impoverished, but rather the degree of their poverty, their perceived choices at the time, and the ability of the broker to encourage and manipulate. The possession of financial resources (i.e. land), the agreement among family members to avoid organ-selling, and the awareness of physical consequences of organ removal were all factors that helped to prevent POOR.

Another interesting factor is the protective power of individuals understanding that the removal of an organ impacts their future ability to use their body for daily work in the community. The economic environment only allows for the use of the body through physical labor or through the alternative of organ sales. NPTORs worried that organ removal would compromise their ability to work, and thus their survival in the community post-transplant. The role of community knowledge cannot be overstated and will be explored further in the implications section. Even so, community knowledge without substantial concerted efforts to reduce poverty may have little effect on the occurrence of TPRO. It can be argued that the individual NPTORs who have not had a kidney removed may at some point in the future experience desperation and need an

alternative to solve their financial problems. They may also come to a time when they are not able to depend on their physical labor to generate enough income for a set of crisis circumstances. The impoverished community and the individual's ability to work could determine their status as a PTOR in the future if their current physical capacity diminishes. In addition, the lack of stable work impacts an individual's ability to earn, despite their capacity to work. Even those who survive by their own work may experience great financial hardship as steady work opportunities do not exist. In these cases, NPTORs are also susceptible to organ removal because of income instability.

The response of the government to generations of persistent poverty has been inadequate. With appropriately designed and funded poverty reduction programs, individuals would be far less likely to have their organs removed for compensation. Study participants explicitly stated that had they received help from the government, they would not have sold their kidney. The implications of this study, along with concrete suggestions to decrease the occurrence of TPRO through both governmental and local level initiatives are provided in the implications section.

### **Consent**

Central to the discussion of TPRO are the concepts of consent and agency. The ability to exercise free will is an essential part of the moral principle of respect for persons (Beauchamp & Childress, 2013; Belmont Report, 1979). Respect for persons prescribes the right of individuals to a "self-chosen plan" through personal autonomy (Beauchamp & Childress, 2013). This plan must be respected as an extension of respect for the individual, based on the intrinsic value of every human being. In decision making, respect requires that the "plan" is self-directed and is chosen solely based on the desires

of the individual. Consent is an extension of the respect for the person, as it assumes the right of the person to choose. Providing adequate consent in health decision making requires that individuals, free of undue influence and coercion, are able to assert their agency and act independently to make their own free choices (Beauchamp & Childress, 2013; Belmont Report, 1979).

In the informed consent process, an individual provides consent for a specific decision at a particular time in a given context. The term choice implies options, to choose or not choose the specific course of action. Information, comprehension, and voluntariness are the three elements that are necessary to ensure informed consent (Belmont Report, 1979). Full informed consent requires knowledge of the risks and benefits of the decision, comprehension of the individual, with the assumption that the individual is mentally capable of deciding, and a voluntary decision by the individual (Belmont Report, 1979).

Members of vulnerable groups may have a compromised ability to provide consent based on their physical, economic, or social status. In particular, the mental and physical capacity of an individual can severely limit autonomous decision making (World Medical Association, 2013). Faden, Beauchamp, and King (1986) explained that decision making capacity can be altered by the presence of “temporary constraints,” such as ignorance and coercion. Ignorance exists when individuals are not given adequate information or if their mental capacity inhibits them from understanding the information. Coercion is the result of the manipulation of an individual in a decision making process when one individual exerts power over the other to gain consent. Individuals with illness or mental disability, children, prisoners, economically disadvantaged individuals, and

those who are institutionalized, are at risk of manipulation and coercion in research (Faden et al., 1986; Belmont Report, 1979; World Medical Association, 2013). For example, the economically disadvantaged are susceptible to manipulation and coercion due to their level of financial hardship.

Researchers and medical professionals must have assurance that the individual is given all necessary information and he/she is able to comprehend the information prior to consenting (Faden et al., 1986). The validity of the consent of the individual is based on the individual's ability to both receive the information and to fully comprehend it. One constraint of the informed consent process that has been identified is the "manipulative underdisclosure of pertinent information" (Faden et al., 1986, p.8). Individuals are not fully consenting to participation or a procedure when they did not receive all necessary information, whether purposefully withheld or not. In this study, the context in which the consent is being sought is also suspect.

Literature exists that examines the role of comprehension in the informed consent process, particularly as it pertains to medical decision making. A literature review of studies on the consent provided prior to surgery, indicates that low education levels, language competency, and low literacy impacted individual comprehension of information during the informed consent process (Jahan et al., 2014; Rothman et al., 2004; Sherlock & Brownie, 2014). Studies have also linked low IQ and impaired cognitive function with poor consent process information recall (Lavelle-Jones, Byrne, Rice, & Cuschieri, 1993). Impaired mental capacity constrains an individual's free will to make a choice when their capacity does not allow for full comprehension of the information they have received.

Individuals from vulnerable populations are “easy to manipulate as a result of their illness or economic condition” and this manipulation diminishes their capacity for self-determination (Belmont Report, 1979, p. 9). This manipulation greatly impacts whether or not their decision on a particular action was made voluntarily. The voluntary desire to take an action, whether that be participation in a study or the approval of the removal of an organ, can be threatened.

Coercion and undue influence are two threats to voluntariness in decision making. Coercion occurs when there is a threat of harm from one person to another in an effort to gain the individual’s compliance (Belmont Report, 1979). Threat of harm could include a threat of physical violence against the individual. Fearing harm, the individual is coerced to agree to a decision out of a desire to avoid physical or other repercussions. In the case of undue influence, compliance is obtained through the offer of a reward from one individual to another to motivate a specific choice (Belmont Report, 1979). Undue influence exists when an individual is incentivized to make a decision that they would not otherwise make, against their own best judgment or desire. In both instances, the means by which the consent was obtained, through threat or inappropriate incentives, negates the autonomy of the decision maker. Coercion and undue influence, while separate concepts, are mechanisms that exploit the desperation and desperate situations of individuals.

The social and economic contexts in which individuals make decisions, particularly with regard to medical decision making, has been studied (Fisher, 2009). Marshall (2007), on behalf of the World Health Organization, published a report that examines the challenges in gaining informed consent in resource-poor settings globally.



Not only does the mental capacity of the individual impact comprehension, as mentioned previously, but so does the social and cultural context. Understanding and comprehension can be compromised by language and cultural constraints (Marshall, 2007). Social position and power inequities have also led to cases of undue influence, where individuals seek participation in medical research because it is the only means by which they can receive medical therapy (MacQueen et al., 2004). Individuals who are living in impoverished communities are particularly susceptible to undue influence in medical research, where access to health services is limited (Marshall, 2007). The voluntary consent of the individual may be compromised, as the reward of study participation may be particularly attractive and alter the free will of the individual. In other words, the individual may feel compelled to agree just on the basis of a particular health need, and not based on interest or desire to participate.

Fisher (2013) argues that examining coercion and undue influence as the only threats to voluntariness neglects to account for “structural coercion” and represents a “narrow” view of threat of harm. Fisher applied the concept examined by researchers studying business ethics and philosophy to the study of informed consent in clinical settings. With regard to biomedical research, structural coercion refers to social, cultural, economic, and political contexts that impact decision making, for example financial hardship or illness (Fisher, 2013). A decision cannot be separated from the context in which it was made. The factors that arise from the context impact the ability of the individual to provide informed consent. Resource-poor individuals may make a decision that they otherwise would not, if the circumstances were different, for example to participate in a clinical research study solely based on economic need (Fisher, 2013).

While this theoretical concept is utilized by Fisher to address how context impacts consent in the clinical research setting, the concept can be applied to the examination of TPRO.

Data gathered from study participants with regard to their lack of knowledge of the procedure and the associated risks and benefits, as well as the feelings of a lack of choice, indicate that required elements of informed consent were not present. While the mental capacity of the individual PTOR is not in question, the circumstances with which consent was obtained from individuals altered the validity of the consent. Findings indicate that PTORs did not make a voluntary decision, as their choice was limited, and the voluntariness of their decision was compromised. Poverty does not completely undermine an individual's ability to make a decision, but in the case of TPRO, it renders individuals choiceless, which in turn, removes their ability to make a choice of their own free will. Given the environment where the decision was made and the position of vulnerability that the individual was in, individuals acted to survive within their economic, social, and physical environment. The consent of PTORs, with regard to their organ removal, is inadequate because of the conditions under which they lived and the way in which consent was obtained.

The organ was removed in an environment where intrinsic (e.g. gender), and extrinsic (e.g. poverty) factors combined to render invalid the consent given by the participants in the study. In the absence of valid consent, the removal of an organ cannot be construed as a 'donation' but must instead be seen as an act of 'trafficking.' Structural coercion constrained the PTORs' ability to provide voluntary consent. Not only did PTORs lack the information and comprehension, but they were subject to three threats to

their voluntariness. In some cases, spouses of PTORs utilized coercion to force an organ removal, while in others, brokers used undue influence to obtain compliance for the organ removal. Most critical to this study, however, is the impact of the economic, social, and political environment on the decision. The vulnerability of the individual, the combination of intrinsic and extrinsic factors, is structurally coercive, and leads to TPRO, through the existence of structural community vulnerability and the abuse of vulnerability by a broker. Preventing further occurrences of TPRO will require elimination, or at minimum, reduction, of all three threats to the individual's ability to make a voluntary decision.

Study findings are consistent with current thinking on the issue that TPRO is a form of human trafficking and is considered trafficking because of the abuse of a person's position of vulnerability (COFS, 2014; UNODC, 2013, UN General Assembly, 2000). The Trafficking Protocol (United Nations, 2000) defines trafficking in persons in terms of the presence of three elements: action, means, and purpose. The full definition of trafficking in persons is available in Table 1 (page 40). Most relevant to this study is the examination of the means by which trafficking occurs. The means by which this occurs is through "coercion, abduction, fraud, deception, abuse of power or a position of vulnerability, and the giving or receiving of payments to achieve consent" (United Nations, 2000, p.2). If one of the described means exist, along with the action and the purpose, the consent of the individual is considered irrelevant (United Nations, 2000). Study findings indicate that the consent provided by the individual PTORs was irrelevant, as the means by which the consent was obtained (abuse of a position of vulnerability and coercion) were abusive. (United Nations, 2000). Current legal frameworks for trafficking

explain that it is not specifically the vulnerability of the individual that makes organ removal for compensation abusive, but rather, the intended exploitation of the vulnerability by the perpetrators (UNODC, 2013). The exploitation of the individual occurs as a result of the structurally coercive environment that impacts an individual's vulnerability and leads to the subsequent abuse of the vulnerability.

However, the perceived role of individual agency is still important, as study participants did not view themselves as victims. In contrast to viewing themselves as victims of a circumstance that led to their kidney removal, participants described their decision. Despite this view, existing legal frameworks define the abuse of vulnerability to obtain an organ as a form of human trafficking, and thus, individuals are considered trafficked persons. The lack of alternative choices made individuals vulnerable and the abuse of that vulnerability impacted consent, regardless of their understanding or recognition of how their vulnerability impacted their status as a trafficked person. Despite the approval of the state governing board for the organ removal, the necessary elements of informed consent were missing and consent was invalid, as supported by study findings.

To participate in this study, individuals were required to provide verbal consent. The distinction between the consent that was obtained for organ removal and for study participation must be explored to understand how the processes differed. The act of obtaining consent and the purpose for obtaining it differentiates the role of the researcher from the trafficker. The purpose of the study was to understand the specific vulnerability factors that led to trafficking, with special regard for the susceptibility of the individual, as opposed to their experience with TPRO that required the abuse of their vulnerability.

The consent of the individual to participate in the study was valid because there was no abuse of their position of vulnerability, contrary to when their organ was removed. The means and purpose by which consent was gained in the two instances varied greatly.

However, in both instances individuals were vulnerable based on intrinsic and extrinsic factors. PTORs were particularly susceptible to manipulation and abuse because of the position of vulnerability in which they were in, as a result of their financial situation and physical well-being. The organ removal made PTORs more vulnerable to abuse as their economic situation worsened as a result of their trafficking status. This was an important factor in developing the research consent process, as the researcher was acutely aware of how desperation impacts consent, and therefore could impact study participation. It was a concern throughout the study that individuals could be participating based on financial need, and not out of desire to share information with the researcher. As discussed in Chapter 3, consent in this study was part of an iterative process. Data from study interviews indicate that individuals were aware of the purpose of the study and the data was collected with extreme attention to each individual's vulnerability and the potential for this vulnerability to impact consent. The decision not to use financial incentives for study participation was purposeful to avoid financial coercion.

Despite this and the concerted consent process that was employed, the potential for individuals to have participated based on a desire to receive a benefit not described or assistance, cannot be ignored. It is also critical to acknowledge that my position as a foreign researcher may have subtly impacted their consent, despite continued efforts to

eliminate all sources of coercion or undue influence. Participant expectations may have altered their decision making process to participate in the study.

### **Implications for Social Work**

The purpose of this dissertation was to explore research questions and to produce findings that could inform policy and practice efforts to prevent compensation for organ removal in India. This study specifically filled a gap in knowledge that has not been addressed, the specific influences that contributed to the occurrence of TPRO in a specific community. Previous studies have examined motivation and have concluded that finances are the motivating factor. This dissertation study differs from previous studies conducted in India (Budiani-Saberi et al., 2014; COFS, 2014; Cohen, 1999; Goyal, 2002) because it examined the role of vulnerability in susceptibility to trafficking, but also explored the impact of protective factors. Methodologically, the inclusion of both individuals trafficked and individuals not trafficked allowed for a clearer understanding of the influences that impacted organ sales occurrence.

This study helps to further the conversation about the specific influences, on multiple levels, that contribute to individual and community susceptibility, in an effort to develop prevention programs. Policy and practice implications that aim to address TPRO on the economic, governmental, community, and family level are provided. Policy and practice recommendations can improve the living donor assessment process, increase deceased donation, prosecute the perpetrators of the organ trade (brokers and medical staff, not PTORs), and improve national and state level response to trafficking. Study findings are examined with regard to social work education and practice implications.

Finally, PTOR-specific assistance programs to support economic stability, health, and mental well-being are also outlined.

**Poverty reduction programs for prevention.** On the governmental level, improvement of local and national programs, particularly the 100 Days Work program, is critical. The Mahatma Gandhi National Rural Employment Guarantee Act (NREGA), is a government livelihood program, also known as the 100 Days Work program, because it guarantees work to unskilled rural households annually (Ministry of Rural Development, 2005). This program has come under fire by Indian researchers for not being the employment guarantee initially described and for the inadequate implementation of the program (Arun, Prakash, & Dipak, 2015). One NPTOR individual described his experience with the program as, *“We have the government scheme, but they aren’t giving us work.”* Both PTORs and NPTORs expressed their disappointment with both the lack of work guaranteed by the program and the lack of income.

While it may be difficult to enact change on the national level, advocating for the improvement of the 100 Days Work program can be a step in supporting income generating activities in the community. Increasing access to resources can have an effect on the number of people who are susceptible to trafficking. Despite the inefficiencies in the government programs, participants remain hopeful that the government will provide assistance, particularly to those who are PTORs. One participant noted, *“We have hope that the government will help us, we heard that those who have donated will get help from the government, but until now we haven’t gotten anything and we don’t know what happened.”* Local community organizations can collaborate with the local government to

understand what may be impacting the ability to work or the receipt of money for the work that has been previously done.

The need for gender appropriate and stable work is a finding that could translate into the addition of incoming-generating activities in the community. Livestock rearing, as well as sewing and other handicraft work, can be done by women from the home, as suggested by study participants. It is critical to explore income pathways to earn from home. Social work practitioners could be instrumental in developing training programs and seeking the funding to provide technical skills trainings to women and men. This can be done in collaboration with local and international organizations that are currently on the ground in the community and which already focus on income generation.

Effective poverty reduction programming must begin with a needs assessment to understand the community and to develop programs that will work within the constraints of the environment. Understanding the needs of the community will help to determine the type of poverty reduction programming that is needed. For example, it is not feasible to provide a small shop for each of the individual trafficked persons, as suggested by many individuals during the interviews. The community cannot support an influx of individual shops and this is not an economically viable solution, so creative solutions must be developed to reduce poverty in a way that includes additional stakeholders such as the government and local community organizations.

**Donor assessment process.** On the policy level, the government of India can use these findings to begin a conversation about the factors that make individuals susceptible to TPRO. In India, the practice of receiving compensation for an organ is illegal. The Transplantation of Human Organs Act (THOA, 1994) was enacted to regulate the



removal of organs and to ensure that commercialization does not occur. It is through this legislation that Authorization Committees, governing boards of medical professionals charged with determining individuals are giving their organs free of socio-economic pressures, exist in every state. One of the primary goals of the committee is to assess whether a person should be able to donate an organ and this authorizing board grants permission for living transplants to occur. One implication of this study is that policies and procedures to improve the AC's functioning can be put into place so that fewer individuals become PTORs.

Understanding the tactics that brokers use to bypass the system and trick the governing officers could be useful in stopping the practice in some cases. A donor assessment tool, as suggested within the literature (Duerinckx et al., 2014; Papachristou et al., 2004), could not only include recommended physical and psycho-social measures, but could also incorporate identified factors and tactics that have been associated with trafficking in persons for the removal of organs. For example, findings suggest that the family can have a great impact on an individual's decision to have an organ removed. It is this fact that is exploited by brokers who circumvented in the donor assessment process with the use of fake identification and hired family members, as described in Chapter 6. By strengthening provisions to ensure true family member status, the process can be more protective and robust.

Changes to the application process can reduce instance of TPRO. Incorporating and expanding interviews with family members may help to identify those who bring individuals who are not actually family members.

Authorization Committee members should be trained on the specific loopholes that are being utilized to gain approval for living organ donation. Not only can study findings inform the revision of the donor assessment tool, but committee members should be able to recognize vulnerability factors of potential donors through training. This addition could increase the rigor of the process overall and equip Authorization Committees across India with an additional tool to make a more informed decision on living donation.

**Law enforcement response.** Community and state law enforcement officers must be aware of the practice of TPRO and the associated factors. Officers should be trained to recognize cases of TPRO and be knowledgeable about how to connect PTORs with local service organizations when possible. Training could educate law enforcement officers about TPRO within a larger human trafficking framework and focus on the protection of the individual PTOR, as opposed to the prosecution.

Law enforcement, both on the state and national level, should examine existing laws (THOA, 1994) to develop strategies and procedures for the local context to identify brokers and other individuals coordinating organ sales. Brokers have a pivotal role in connecting vulnerable individuals to organ recipients. The THOA outlines specific penalties for “commercial dealings in human organs” which include receiving or making payment for an organ, initiating or negotiating an arrangement, publishing or distributing an advertisement, and inviting persons to supply payment for a human organ, among other activities (THOA, 1994). The penalty for engaging in these activities is a term of imprisonment for less than two years and a fine of less than ten thousand rupees (\$153 USD).

During data collection, study participants indicated that brokers in the community continue to operate despite common knowledge of these activities among community members. Community members cannot be expected to risk their safety to identify brokers, but local law enforcement must dedicate resources to identify these individuals to influence them not to engage in TPRO. Once individuals are identified, their role in facilitation must be examined and the law must be enforced to prosecute brokers. The THOA not only describes punishment for brokers, but also for medical professionals that conduct illegal transplants. The role of medical professionals was not explored in this study, but should be examined as part of an overall law enforcement strategy to end TPRO by punishing those who break the law.

Beyond punitive action against brokers to stop organ sales, local law enforcement should work with existing brokers and PTORs to deter individuals from earning an income through organ removal facilitation. In this study, one broker was identified as a previously trafficked person. Deterring brokers from engaging in organ sales coordination is only possible if there are stable income generating opportunities, as discussed previously.

**Medical response.** Physicians who conduct commercial transplants should be held accountable and face punishments, just as brokers should. Medical professionals who perform commercial transplants should be subject to various professional consequences to include fines, loss of medical license, and temporary or permanent restrictions on scope of practice. For example, a physician may be barred from performing surgery or practicing in a certain state or hospital for a prescribed period of time. If the physician is a repeat offender, a restrictive ban should be implemented. It is

critical to explore mechanisms to increase physician accountability. Consequences for medical professional engagement in commercial transplants are included in existing laws (THOA, 1994), but a concerted effort should be made to punish offenders, as well as increase the severity of punishments.

The medical community should self-govern and regulate against TPRO as described by their Hippocratic Oath. It is not unreasonable to expect professional ethics and standards. The practical implication of this recommendation could include the development of an anonymous voluntary reporting system where physicians could report the unethical practices of their colleagues, without fear of professional or personal repercussions.

Medical professionals should also be trained on vulnerability factors. While the state Authorization Committees are tasked with determining that individuals are not giving their organ for socio-economic reasons, physicians should also be aware of the factors that make individuals susceptible to TPRO.

Medical professionals have also been on the forefront of expanding deceased donation in India (Mohan Foundation, 2016). They should continue to dedicate time and resources in building a robust system for tissue and organ transplantation. On the national level, TPRO can be reduced with a concerted effort to increase deceased organ donation in India. The Mohan Foundation of India, along with the National Organ and Tissue Transplant Organization, is currently expanding the use of a national organ sharing network and utilizing programming to educate the public about the role of deceased donation (NOTTO, 2014). Medical professionals, particularly physicians, can contribute to existing efforts in coordination with national and state level organizations. Study

findings support the need for improved coordination of legal organ sharing among donors and recipients. The THOA amendment of 2011 included the requirement of a National Tissue Bank. There is a push in India to create a way to fill the gap in demand for tissue and organs through non-exploitative ways to include deceased donation and legal living organ donation.

This gap in demand for tissue and organs could be narrowed with the exploration of a model for presumed consent. Presumed consent is a system where individuals are assumed to donate their organs upon death, unless they specifically opt out of the program. Presumed consent drastically increases the number of available organs, thus decreasing the need for living organ donation. This recommendation is not new, as researchers and policy analysts have been discussing the potential for this model in India. Researchers have highlighted some problems with the model to include risk for abuse based on educational disparity and social stratification (Dar, 2016) and potential for implementation issues (Kumar & Valsangkar, 2014). While ethical considerations limit the support for presumed consent (Kumar & Valsangkar, 2014), policymakers, researchers, and physicians should continue to debate the appropriateness of the model within India, but with caution.

**Community education and awareness.** Results from this study indicate that there are specific ways that social work practitioners could develop programs with targeted prevention goals on the community level. Education could be an important tool in reducing TPRO in the community. One targeted prevention program on the community level could include the creation of programming that focuses on the risks of TPRO, as findings indicate that awareness of the consequences may have deterred some individuals

and families. Specifically, this programming could emphasize the impact of organ removal on individual ability to work post-transplant. These programs can be enacted with the cooperation of key field partners. Enactment of this type of program would require safety planning and assessment. However, efforts to bring PTORs together in this community have been successful in the past and this type of intervention is worth exploring.

Understanding that access to resources is critical, there are numerous ways in which individuals can gather new information to both earn more income and to become engaged with community financial institutions. Specifically, educational programs can be developed to increase knowledge of community saving and borrowing organizations and encourage participation. However, financial literacy education and introduction to borrowing and saving techniques alone are insufficient, as they are not income-generating activities. All community level economic empowerment programs must be provided in conjunction with programs that increase earning capacity and access to work opportunities.

It could be beneficial to provide community and household-level training on the benefits of banking and saving. As of 2014, 53% of Indians age 15 and older had an account at a financial institution (World Bank, 2014). In 2014, the Indian Government unveiled a plan to provide bank accounts to the country's poorest citizens, particularly those in rural areas, with a goal of covering 75 million households by 2018. According to the Indian Government, in the state in which this study occurred (omitted for confidentiality purposes), there are 18 million rural accounts as of February 2017 (PMJDY, 2017). (Data on specific communities are not available.) With the opening of

millions of new accounts, financial empowerment programs are needed to educate new account holders on how to manage their accounts and how to interact with financial institutions. It remains important to ensure that not only people from the specific community where this study was conducted are connected to a bank, but that they acquire banking and saving skills. International, national, and local organizations are currently providing financial empowerment programs in India (Chhaya CDC, 2017; SEWA, 2017). These organizations can be used as models to develop a program that focuses on community banking and saving.

Micro-credit loans, small loans that are given to women to provide them with the ability to become small business entrepreneurs (Grameen Bank, 2018), could also be considered as a community level financial intervention for women. Small loans are provided to women in developing nations with the expectation that the loans will be repaid once the business is established and successful. Research, however, indicates that debt and loan repayment are linked to TPRO, as individuals have sold an organ to settle a financial debt (Moniruzzaman, 2014). Specifically in Bangladesh, where micro-finance originated, evidence exists that individuals have sold their kidney to pay back a micro-credit loan (Cousins, 2014). Small loan programs that were intended to lift individuals out of poverty may be increasing their vulnerability to TPRO, as they struggle to find the means to repay the initial loans. Despite this, variations of micro-credit programs could be considered as a part of an overall strategy to empower women economically and reduce the occurrence of TPRO.

#### **Organizational collaboration for PTOR identification and assistance.**

Organizations that are serving individuals within the community should coordinate

efforts to identify individuals who are at risk of TPRO, for example victims of other forms of trafficking. Anti-trafficking organizations, non-governmental organizations, faith-based organizations, and local community organizations should partner to develop a system that identifies individuals and provides the necessary referral to services. Identification of at risk individuals through organizational collaboration can help prevent future cases of TPRO, as those at risk can be connected to services.

Coordination among organizations is also critical for addressing the needs of PTORs. To prevent generational organ sales among families, PTORs must be provided with economic assistance, medical follow-up, and psychosocial services. As previously described, physical consequences post-transplant severely decrease the ability of PTORs to work in their community which greatly limits their ability to survive. If one member of the family cannot earn, others in the family become more susceptible to trafficking as the financial situation of the household is increasingly dire. PTORs who were young have a greatly diminished capacity for hard labor as a result of the surgery. Many PTORs described their inability to work and the economic strain that they experienced. Data suggest that in some families, multiple individuals had their organ removed for economic reasons. Providing financial assistance in the form of general cash assistance, as well as training programs for jobs that do not require physical labor, can help reduce the occurrence of generational TPRO. Assistance and services for trafficked persons should be provided by the government in coordination with local organizations who understand the specific needs of the individuals. Local organizations and non-governmental organizations should advocate for funding for PTOR assistance.



Following surgery, most PTORs reported that they returned to their community and did not receive the follow-up medical care that is standard post organ removal. As a result, the physical consequences including pain at extraction site, fatigue, and inability to lift weight were exacerbated. Proper medical care services should be provided to PTORs to ensure their long term health and to mitigate the effect of surgery on their body and functioning. Psychosocial services, to include the processing of psychological harm is also worth exploring as a follow-up service for trafficked persons. While PTORs did not view themselves as victims of their own situation or recognize that they have been harmed, facilitated discussion could be beneficial, in conjunction with financial and medical services to address immediate needs.

In 2014, the United Nations Voluntary Trust Fund for Victims of Human Trafficking (UNVTF) awarded the Coalition for Organ-Failure Solutions a three-year grant to address the needs of PTORs through medical, legal, and livelihood support programs (UNVTF, 2014). Through livelihood programs, individuals have received livestock and will be connected to training programs that teach them how to rear the animals, as well as how to breed. This program can be expanded through a collaboration with local organizations in the community, to include education on tailoring and handicraft making. Before developing the program, a needs assessment could help determine what specific livelihood programs would be most beneficial in the community. The United Nations is supporting the efforts of organizations that are aiming to increase the resources of those who have been trafficked for organ removal and efforts could be expanded to reach those who are susceptible to TPRO.

**Family-level interventions.** Beyond individual level implications, family programs could be developed that may reduce TPRO. The development of a family pact or decision could potentially be helpful in reducing kidney sales. Any family level intervention that is developed would require the buy in from all parties, with particular focus on the culture and organization of the family. Programs would likely be most successful if developed at the local level by community and faith-based organizations that understand the cultural and social context and have some influence on family life.

**Social work education.** Findings from this study could be utilized to educate social work students broadly about vulnerability and protective factors within international contexts, but also inform work with clients in domestic settings. Understanding and knowledge of the overall definition of human trafficking, to include trafficking in persons for the removal of organs, can also be expanded and incorporated in to MSW coursework. TPRO is a lesser known and understood form of trafficking, and with increased exposure, students can learn about how the practice is situated within the larger human trafficking context. Specifically, study related findings could be incorporated in to MSW curriculum, particularly in courses exploring poverty, global and social development, and gender and women's studies. Further, social work student can be helped to recognize how interventions on multiple levels can add protective features in community where trafficking occurs.

### **Limitations**

One of the limitations in this study was the small sample size. Although this study was exploratory and context-specific, a larger sample size may have been helpful in further delineating influences, or in comparing the experiences of PTORs and NPTORs.

Cultural and religious factors could have been explored more if there was representative sample of individuals. While this qualitative sample was not crafted to represent the proportions of varied groups, efforts were made to include study participants who spoke two different languages and represented three different religions.

Individuals who became study participants chose to participate in the study, and therefore, one limitation is the sample as a whole. It is possible that individuals chose to participate with the hope that they would receive a benefit, despite the information they received during the consent process and throughout the interview. Regardless of this information, the perceived ability to benefit may have impacted study participation.

It also may be that the most vulnerable individuals, both PTORs and NPTORs who were susceptible to kidney sales, did not participate. Their lack of participation could be due to many reasons including the fact that they had not been previously identified by community organization staff, or due to fear of repercussions from brokers, law enforcement, or government officials. Additionally, because recruitment was done with the assistance of the community agency, only individuals who were affiliated or connected with the agency were approached to participate in the study.

Some PTORs had their kidney removal years ago. One limitation of the study was the participant's ability to recall events. While in most cases participants could remember the events, there were times when they simply could not recall details. The time since the event may have also impacted their understanding of the situation, particularly for those who had their kidney removed more recently. The time that the individual had to process the event may have had an effect on how they processed the organ removal.

Data gathered on the donor assessment process and the role of brokers in the process was collected solely from study participants. It was not possible to interview brokers or Authorization Committee members, so findings are presented based only on the recall of the study participants. Not only can time impact an individual's ability to remember a particular event, but can alter their understanding of the event.

As a foreign researcher, my status as a young Caucasian woman undoubtedly impacted the results of the study. My status may have impacted data collection and analysis, as described in Chapter 3, but also the way that participants interacted with me and responded to questions during the interview. Participants may have felt that they should respond in a specific way, that I was interested in a specific response. Social desirability bias may have led to participants answering questions in a more or less favorable light, according to their perceptions about what the answer should be. The use of language interpreters and research assistants from the local organization may have also affected the responses of study participants. While it was a priority to explain that participation would not impact participant standing with the local organization, study participants may have drawn a connection between their participation and future assistance.

### **Future Research**

Future research on trafficking in persons for the removal of organs should further explore the understanding of consent and victimization. While this study examined these topics through the exploration of factors, more in-depth analysis of the individual's thinking about their agency needs to be completed to understand both limits to, and the ability to exercise, their own agency.

Future research should also expand the study of the process by which PTORs weigh decisions and how vulnerability impacts trafficking status in communities inside and outside of India. This can be assessed in another state in India and compared conceptually to those from this study. Specifically, what are the similarities across communities? While this study was context-specific, researchers should track processes from across multiple communities to gain a better understanding of TPRO as a whole and how vulnerability is manifested both similarly and differently at numerous locations.

Poverty is likely the factor that contributes to TPRO in all communities where PTORs reside. Poverty originated organ removal (POOR) explains that individuals are left with less choice due to their poverty and this leads to the trafficking of their kidney. In this study, the need for financial resources for daily living or for planned (wedding of daughter) and unplanned stressors (illness of family member) impacted individual status as a PTOR. Future research can explore a more nuanced understanding of the community- and individual-level poverty and study the differences in the causes of poverty. For example, in some communities where TPRO occurs, repayment of debt is a main motivating factor for individual organ removal, whereas in other communities, a natural disaster is the catalyst for widespread organ sales. It would be interesting to explore how these communities differ as some experience persistent poverty as a result of lack of economic opportunity, while other communities suffer sudden loss of industry post-disaster. More specifically, I am interested in how environmental factors, particularly related to how the actual community location (proximity to bodies of water and larger cities, weather patterns and impact of climate change), impacts susceptibility to TPRO. Reports suggest that environmental disasters wipe out industry and provide a

breeding ground for brokers to exploit the misfortune of individuals (COFS, 2014; Cousins, 2016; Forum for Protection of People's Rights Nepal, 2016). It is also of interest to explore insurance strategies could help mitigate the negative effects of natural disasters and could reduce occurrence of TPRO.

As an extension of this dissertation, evaluations could yield a better empirical understanding of how programs can affect the occurrence of TPRO. The 100 Days Work Program should be examined for its effectiveness in reducing rural poverty in India and in providing stable income for those who are susceptible to trafficking. In addition to an evaluation of existing government programs, future research could also focus on specific programs developed to address the issue in the community. For example, the implementation and results of a family level program should be studied to determine if there is efficacy and positive outcomes. My preference is to conduct research that is practical in nature and can yield results that can be used to adapt existing programs or inform future policies.

Additional research on the role of the Authorization Committees as the assessor of living donation in India is also needed. This policy analysis could answer questions about the role of the donor assessment and allow for critical analysis of the process, with the goal of developing an evidence-based assessment tool. All information on the donor assessment process was reported by participants. If access to the Authorization Committee is granted, a full analysis of the current policies and procedures could yield valuable information.

Data on the role of the brokers was also collected solely from study participants. Future research could include exploring the perspectives of brokers to fully understand

how TPRO occurs in the community. If feasible, brokers could provide insight on how recipients are connected to trafficked persons and how the transplant is coordinated through medical centers. It would also be interesting to explore the process by which trafficked persons become brokers.

## **Conclusion**

Individuals living in this community are vulnerable due to the economic environment, but the way that their vulnerability is expressed impacts their trafficking status. Data illustrates that influences exist on the economic, cultural, family, and individual levels that either protect individuals or increase their vulnerability to being targeted for organ removal. It is the combination of poverty, coupled with the presence of organ brokers who work within an inadequate donor assessment system, that create an environment where Poverty Originated Organ Removal (POOR) occurs. Conversely, findings suggest that positive influences exist, such as family decisions/pacts to avoid organ-sales, and community knowledge sharing that may protect an individual from becoming a trafficked person. Policy makers, practitioners, and government officials should be aware of the cultural context and other influences that may contribute to an individual's susceptibility to trafficking in persons for the removal of organs in an effort to end the practice.

**Appendix A.****Person Trafficked for Organ Removal (PTOR) Data Collection Sheet**Demographics

Age	_____
Age at which the donation took place	_____
Gender	male    female
Job	_____
Current work status	_____
Work status at time of the donation	_____
Monthly income (Rs.)	_____
Approximate monthly income at the time of the donation (Rs.)	_____
Schooling	_____
Marital status	married    single    widowed    separated    divorced
Number of children	_____
Age of children	_____    _____    _____    _____    _____
Children's schooling	_____
Total number in household	_____
Ethnicity	_____
Country of Origin	_____
Region of Origin	_____
Religion	_____
Primary Language	_____
Organ removed	_____



Year of organ removal \_\_\_\_\_

City of organ removal \_\_\_\_\_

Transplant center where organ removal occurred \_\_\_\_\_

Amount promised for organ \_\_\_\_\_

Amount paid for organ \_\_\_\_\_

**Description of physical environment.** This description may be of the donor's living environment or interview environment, depending on location of interview. It may also include a description of the surrounding environment that is observed during travel to the interview site.

Attention to:

infrastructure (roads, community centers)

availability of resources (electricity, water, sanitation, food)

proximity to other villages, towns

transportation options

**Appendix B.****Person Trafficked for Organ Removal (PTOR) Interview Guide**

(interviews to be conducted in a conversational format)

**Background and Introduction**

1. How long have you lived in this community?
2. Have you always lived here?
  - a. If not, where did you move from?
  - b. Why did you move here?

**Vulnerability Factors and Motivation**

3. What was your life like before your organ was removed?
4. What was your financial situation prior to your organ removal?
5. What was your biggest struggle at the time?
6. What is the main reason that you had your kidney removed?
7. Did anything else motivate you to have your kidney removed?

**Recruitment and Targeting**

8. How did you learn of the opportunity for organ removal?
9. Have other family members or friends had an organ removed? If yes, how did they learn about it?
10. Did someone approach you about having a kidney removed? If so, please explain.

**Donor Assessment/Pre Surgery Experience**

11. What was the process of applying to have your kidney removed like?
12. What paperwork was required? Did you sign paperwork?
13. What medical tests were done prior to organ removal?

14. Did you meet with someone from the government or the transplant center who determined if you were allowed to have your kidney removed? Please explain.

15. What did the doctors tell you before you had your kidney removed?

16. Did anyone ask you why you wanted to have your kidney removed? Government official? Transplant Center employee? Please explain.

If so, what was your response?

17. When you were waiting in the hospital before the operation, what were you thinking?

18. What do you remember most about the day of your operation?

#### Deception and Coercion

19. Did you feel tricked by anyone during the process? Please explain.

#### Post-transplant

20. What is your life like after surgery?

21. What would you say to others considering having an organ removed?

#### Government

22. What is your opinion of the local government?

23. If you were an officer, what would you do to stop kidney sales?

#### Reflection

24. How do you feel about your decision?

25. What could have prevented you from selling?

26. Is there anything that could have changed your mind? If so, what?

27. Please provide any additional information that you wish to share.

**Appendix C.****Non Person Trafficked for Organ Removal (NPTOR)- Data Collection Sheet**Demographics

Age \_\_\_\_\_

Gender                      male    female

Job \_\_\_\_\_

Current work status \_\_\_\_\_

Work status at time of the time when you gained knowledge of kidney sales

Monthly income (Rs.) \_\_\_\_\_

Approximate monthly income at the time of knowledge of kidney sales  
(Rs.) \_\_\_\_\_

Schooling \_\_\_\_\_

Marital status              married    single    widowed    separated    divorced

Number of children \_\_\_\_\_

Age of children              \_\_\_\_\_    \_\_\_\_\_    \_\_\_\_\_    \_\_\_\_\_    \_\_\_\_\_

Children's schooling \_\_\_\_\_

Total number in household \_\_\_\_\_

Ethnicity \_\_\_\_\_

Country of Origin \_\_\_\_\_

Region of Origin \_\_\_\_\_

Religion \_\_\_\_\_

Primary Language \_\_\_\_\_

**Description of physical environment.** This description may be of the individual's living environment or interview environment, depending on location of interview. It may also include a description of the surrounding environment that is observed during travel to the interview site.

Attention to:

infrastructure (roads, community centers)

availability of resources (electricity, water, sanitation, food)

proximity to other villages, towns

transportation options

**Appendix D.****Non Person Trafficked for Organ Removal (NPTOR)- Interview Guide**  
(interviews to be conducted in a conversational format)Background and Introduction

1. How long have you lived in this community?
2. Have you always lived here?
  - a. If not, where did you move from?
  - b. Why did you move here?

Family and social support

3. How would you describe your relationship with your family members (e.g., spouse, children, parent)?
4. How would you describe your relationship with your neighbors?
5. If you told your wife/husband that you wanted to sell your kidney, what would they say?

Opportunities

6. What are your opportunities to earn an income?
7. What are your choices for work?
8. What opportunities are there for learning new things?
9. What type of work would you like to do?
10. How do opportunities differ for men and women?

Commercial donation knowledge

11. How did you learn of the opportunity for organ removal?
12. Have other family members or friends had an organ removed? If yes, how did they learn about it?
13. Did someone approach you about having a kidney removed? If so, please explain.

Decision-making process

14. How did you decide not to have a kidney removed?
15. Did you seek the advice of anyone when making your decision? If so, please explain.
16. Was your decision influenced at any point by others? Please explain.
17. How long did you consider the options before making a decision?
18. Did your family members support your decision? Please explain.
19. How do you feel about the decision that you made?

Government

20. What is your opinion of the local government?
21. If you were an officer, what would you do to stop kidney sales?
22. Please provide any additional information that you wish to share.

## Appendix E. Application for Approval for Transplantation from Living Donor

**FORM 11**  
APPLICATION FOR APPROVAL OF TRANSPLANTATION FROM LIVING DONOR  
(To be completed by the proposed recipient and the proposed living donor)  
(Refer rules 5(3)(d), 5(3)(e) and 10)

To be self attested  
across the affixed  
photograph  
without disfiguring  
face

To be self attested  
across the affixed  
photograph  
without disfiguring  
face

Photograph of the Donor Photograph of the recipient

Whereas I ..... S/o, D/o, W/o, Shri/Smt. .... aged .....  
residing at ..... have been advised by my  
doctor ..... that I am suffering from ..... and may  
be benefited by transplantation of ..... into my body.

And whereas I ..... S/o, D/o, W/o, Shri/Smt. ....  
aged ..... residing at ..... by the following reason(s):-

a) by virtue of being a near relative i.e. ....  
b) by reason of affection/attachment/other special reason as explained below :-  
.....  
.....

I would therefore like to donate my (name of the organ) ..... to  
Shri/Smt. ....

We ..... and .....  
(Donor) (Recipient)

hereby apply to competent authority / Authorisation Committee for permission for such transplantation to be carried out.

We solemnly affirm that the above decision has been taken without any undue pressure, inducement, influence or allurement and that all possible consequences and options of organ transplantation have been explained to us.

**Instructions for the applicants:-**

- Form 11 must be submitted along with the completed Form 1 or Form 2 or Form 3 as may be applicable.
- The applicable Form i.e. Form 1 or Form 2 or Form 3 as the case may be, should be accompanied with all documents mentioned in the applicable form and all relevant queries set out in the applicable form must be adequately answered.
- Completed Form 5 must be submitted along with the laboratory report.
- The doctor's advice recommending transplantation must be enclosed with the application.
- In addition to above, in case the proposed transplant is between unrelated persons, appropriate evidence of vocation and income of the donor as well as the recipient for the last three years must be enclosed with this application. It is clarified that the evidence of income does not necessarily mean the proof of income-tax returns, keeping in view that the applicant(s) in a given case may not be filing income tax returns.
- The application shall be accepted for consideration by the competent authority / Authorisation Committee only if it is complete in all respects and any omission of the documents or the information required in the forms mentioned above, shall render the application incomplete.
- When the donor is unrelated and the donor and/or recipient belong to a State/Union Territory other than the State/Union Territory, where the transplant is intended to take place, then the Tehsildar or the officer authorised for the purpose of the domicile state of the donor or recipient as the case may be, would provide the verification certificate of domicile of donor/recipient, as the case may be as per Form 20. The approval for transplantation would be considered by the authorisation committee of the State/District/hospital (as the case may be) where the transplantation is intended to be done. Such verification Certificate will not be required for near relatives including cases involving swapping of organs (permissible between near relatives only).

We have read and understood the above instructions.

Signature of the Prospective Donor

.....

Address for correspondence:

Date:

Place:

Signature of Prospective Recipient

.....

Address for correspondence:

Date:

Place:



## Appendix F. Community Landscape Pictures



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