

**A PROPOSED ETHICAL FRAMEWORK FOR THE PSYCHOSOCIAL EVALUATION  
OF THE LIVING KIDNEY DONOR**

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This thesis argues that living kidney donation (LKD) is ethically justified, despite the donor's exposure to its inherent risks and harm, because permitting justified cases of LKD upholds the autonomous decision of the donor to pursue his/her life values and direction. Consideration of the psychological and emotional benefits of LKD and the harm from being prevented to donate allows a more comprehensive perspective of LKD. Medical and psychosocial evaluations of prospective donors function as procedural safeguards. These evaluations aim to protect the well-being of donors by minimizing the risks to the donor, while recognizing the donor's interest in donation and rights of autonomous decision making. Evaluations also reveal pertinent information to transplant professionals to help them weigh the risks and benefits of LKD specific to individual prospective donors. For the LKD to move forward, a prospective donor must meet established medical and psychosocial criteria.

In Singapore, the Human Organ Transplant Act (HOTA) charges a medical social worker with performing the psychosocial evaluation of the prospective donor, and this evaluation is regarded as the expert review which a nationally-appointed transplant ethics committee relies upon in authorizing applications for living kidney donations and transplants. The thesis presents assessment domains for this psychosocial evaluation of the donor, connects these domains to normative principles purporting to justify their inclusion, and highlights those domains that may raise ethical challenges. The thesis discusses the psychosocial evaluation process as currently

undertaken in Singapore, and how the inclusion of a collateral person, as contemplated by the HOTA, can be ethically problematic. While social workers are well-suited to conduct the psychosocial assessment because of their training, experience and the normative commitments of their profession, their involvement also raises some ethical concerns that are discussed.

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## **PREFACE**

This work would not have been possible without the direction and inspiration of the wonderful people on my thesis committee. I will apply the lessons that I have learnt from them in my future work with transplant patients and in helping shape transplant practice and policy in Singapore.

To my thesis director, Dr. Lisa Parker to whom I owe a debt of gratitude that I can never repay. She challenged and inspired me to believe that pursuing this M.A. Bioethics degree concurrently with a Ph.D. Social Work degree was possible. I have benefited tremendously from her brilliance, guidance and support; her patience, generosity, commitment and dedication to excellence as a teacher are qualities that I will strive to emulate. Lisa, I could never thank you enough.

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And to my beloved family that I am so fortunate to have: I thank you with love.

Above all, I thank God who provides for my every need.

Give thanks in all circumstances. 1 Thessalonians 5:18

## 1.0 INTRODUCTION

Living donor kidney transplant (LDKT) is the optimal treatment for end stage renal disease. It promises better quality of life and survival rates for the recipient, has increased organ viability compared to use of a deceased donor's kidneys, reduces transplant waiting time, is more cost-effective, benefits society by reducing the transplant waiting list and contributes to better utilization of healthcare and societal resources [1-3]. Different labels are used to refer to different types of relationship between the living donor and recipient. In some literature or transplant programs, for example, a related donor is one who shares consanguinity with the recipient, whereas elsewhere, a related donor can be related by consanguinity or through marital ties. Living donors may be intra-familial (related either biologically or by marriage or adoption), emotionally related (such as a domestic partner, friend or colleague), or unrelated, i.e., without a pre-existing relationship with the recipient. Terms such as 'altruistic donor', 'anonymous donor' and 'Good Samaritan donor' have been used to refer to the unrelated donor. Who may serve as a living donor, and how these terms are parsed in Singapore is specified below. Unless differentiated in the thesis, 'related donor' will be used to refer to both intra-familial and emotionally-related donors. Also, potential donors and potential recipients are referred to as 'donors' and 'recipients', respectively.

Irrespective of the donor-recipient relationship, living kidney donation (LKD) poses ethical issues because the act of donating a kidney transforms a healthy person to a patient, who

undertakes physical and medical risks primarily for the benefit of the recipient [4-7]. The discussion on LKD-associated harm is expanded in section 3.1.1.

Additional issues, beyond the scope of this project, surround LKD; these include the appropriateness of regulated or unregulated markets for organs, payment of LKD, and minors serving as donors. Paid financial incentives for organ donation are prohibited in many countries, including Singapore.

In view of the ethical challenges surrounding LKD, legislative and regulatory guidelines have been introduced in various parts of the world to guide assessments and approvals for LKD and LDKT, and in part to ensure that these procedures are ethically carried out. In Singapore, the Human Organ Transplant Act (HOTA) provides the legislative framework for organ donation and transplantation [8]. This thesis discusses LKD based on the HOTA directives and that of Singapore's geographic, demographic, cultural and policy contexts.

The promulgation of HOTA in 1987 established an opt-out system for deceased donor kidney donations in accidental deaths. It has since undergone various amendments and expanded to address brain death deceased donor organ donations and living donor organ transplantations. In short, HOTA “makes provision for the removal of organs for transplantation, for the prohibition of trading in organ and blood...” [8]. The Amendments to HOTA and their corollary service directives relevant to the discussions in this thesis include the following:

- 1) Living organ donors can be living-related (first degree relative, second degree relative, and spouse), emotionally-related where there is “a well-defined and established relationship which would justify the donor being willing to undertake mortality and morbidity risk without inducement or coercion,” or unrelated, where there is no pre-existing relationship between the donor and recipient.

- 2) Living organ donation must be altruistic, and requires full, voluntary and informed consent of the donor.
- 3) Sale of organs and arrangement for sale of organs are prohibited.
- 4) Reimbursements are permitted for justifiable and reasonable expenses incurred by the donor consequent to donating a kidney. These include, for example, costs of travel, accommodation and loss of earnings during the kidney donation period.
- 5) A three-person transplant ethics committee (TEC) from a national panel shall evaluate applications for living donor organ transplants. The TEC is composed of a doctor from the transplant hospital who is not involved in the care of the donor and intended recipient, an independent doctor not employed or associated with the transplant hospital and a community lay person. The TEC is charged with the duty of exercising “adequate scrutiny and with a high level of certainty that the donation is altruistic” and that their decisions should consider Singapore’s public interest and community values.
- 6) A social worker is to provide a detailed psychosocial evaluation of the donor to the TEC.
- 7) The TEC’s unanimous and written authorization is required before a living organ transplantation can proceed.

The TEC’s decision on a donor-recipient’s LDKT application is final; and if not approved for transplantation, the same donor-recipient pair cannot receive an LDKT in any transplant programs in Singapore. The TEC is not obligated to provide reasons for not authorizing an LDKT application [8].

HOTA states that a (medical) social worker must engage in the psychosocial evaluation of prospective living organ donors, and this psychosocial transplant evaluation report constitutes part of the expert review that the TEC relies upon when deliberating authorization for living

donor organ transplantation. Because of the weight TEC places on the social worker's donor psychosocial evaluation report, the social worker can feel significant burden in fulfilling this professional duty, especially because the HOTA does not offer clear specification of the roles of the evaluating social worker, even though it outlines the responsibilities for the transplant program, transplant physicians, donors and recipients, and the TEC.

In response to this lacuna, this thesis aims to 1) to articulate an ethically justified framework for the psychosocial evaluation of the prospective living kidney donor, and 2) to propose parameters for the role of the social worker in the donor evaluation process. The project's impetus is the need for an ethically-guided, comprehensive psychosocial evaluation framework that considers Singapore's unique multi-cultural values and legislative context. In this project, I will explain the ethical warrant for including a psychosocial evaluation of prospective living kidney donors as part of the overall evaluation of such donors, and articulate criteria that may appropriately be used to assess such donors, as well as the ethical foundation for those criteria, i.e., the ethical values or principles that support inclusion of each criterion in the psychosocial evaluation process.

In chapter two, I will describe the donor evaluation process, with its medical and psychosocial evaluation components, and briefly explain why it is ethically appropriate to conduct a medical evaluation and a psychosocial evaluation of prospective donors. This is followed by the third chapter which addresses the ethical challenges in and ethical justifications for LKD before presenting the criteria to be employed in the psychosocial evaluation and the ethical principles and normative values that support inclusion of each criterion.

The fourth chapter focuses on the psychosocial evaluation process, and analyzes the ethical appropriateness of involving a collateral person in the evaluation interview. In the fifth

chapter, I will explain why those with training in social work—or similar training or skills—are particularly well-suited to conduct the psychosocial evaluation. I will explain why their skills, competencies, training, and social role are particularly salient to this psychosocial evaluation. This will involve some discussion of the values and goals of social work, in relation to the goals and values grounding the donor evaluation process. In this section I will also explain why it is important for social workers to adhere to the criteria presented and to avoid introducing or relying on their personal ethical values in the psychosocial evaluation.

## **2.0 DONOR EVALUATION PROCESS**

### **2.1 Medical and Psychosocial Evaluations of LKD**

The underlying premise of the thesis is that ethical conflicts in LKD notwithstanding, LKD is an ethically-sound medical risk for the donor to undertake when accompanied with proper donor medical and psychosocial evaluations to determine the donor's fitness to donate. Donor evaluations are performed by a multi-disciplinary team and are conducted over a few sessions. In the USA, the Centers for Medicare and Medicaid Services has mandated the medical and psychosocial evaluations of the living donor since 2007 [9]. In Singapore, the HOTA also stipulates that such evaluations are compulsory. The donor medical evaluation consists of a detailed physical examination, renal function tests, cardiovascular risk assessment, assessment for any malignancies and infections, immunologic testing (including blood typing and cross-matching), an evaluation of the donor's and the family's medical history, and a determination of any contraindications for LKD [10-12]. The objectives are mainly to uncover conditions that may increase the donor's donation risks and to prevent the transmission of any diseases from donor to recipient [11].

The Consensus Statement on Live Organ Donors [13]—hereafter referred to as the Consensus Statement—provides practice guidelines for evaluating the psychosocial suitability of the prospective living donor with the aim of reducing or avoiding undesirable consequences to the donor. The psychosocial evaluation focuses on the donor's psychological, psychiatric and

social functioning, and psychosocial risk factors that may affect the outcome of LDKT. Another component of the psychosocial evaluation is the determination of the donor's ability to provide informed consent, which would require the donor to demonstrate competence in decision making and voluntariness in his/her decision to donate a kidney. Psychosocial evaluation protocols can function as procedural safeguards of donors' interests, and several have been suggested with goals reflecting those stipulated in the Consensus Statement [14-19]. These goals include an assessment of the psychosocial, emotional and social stability of the donor. This assessment may also suggest necessary interventions on donor factors that can affect the LKD outcome or may rule out donors who are unsuitable. Other stated goals are to assess the donor's capacity to provide informed consent and to determine the degree of voluntariness in the donor's LKD decision.

Despite HOTA's mandate for a psychosocial evaluation of the donor and its regard for the social worker's report as an expert review for the TEC's deliberation and authorization of the LKD and LDKT, only broad goals have been suggested for the evaluation. These are: ascertainment of the full, voluntary and informed consent of the donor and altruism in LKD; and the LKD motivation and decision is one "free from inducement, influence, duress or coercion" (psychological, financial or otherwise) [8].

## **2.2 Ethical Justification for Donor Evaluation**

In view of the potential risks of LKD, performing medical and psychosocial evaluations to ensure the donor's candidacy and safety should be part of ethical care for the donor. There is considerable variation in the degree to which different transplant programs tolerate the medical and psychosocial risks to LKD presents to the donor [11]. Transplant programs differ on their

degree of restrictiveness about the medical acceptability of the donor [20]. Similarly, transplant programs vary in what constitutes an LKD psychosocial evaluation, and there are no standardized criteria for this evaluation and determination of the acceptability of a candidate donor [17, 18, 21]. The universal goal in the donor evaluation is to maximize the well-being and minimize the physical and psychosocial risks to the donor. Without comprehensive medical and psychosocial donor evaluations, the risks and potential benefits that donation presents to a particular candidate donor cannot be understood. Moreover, the psychosocial risks and potential benefits for a particular candidate donor are related to the person's particular motivations for donating, which cannot be adequately understood without individual evaluation. The donor evaluation allows transplant professionals to weigh the potential benefits and harm of LKD to the donor, which in turn allows them to assess whether the donor should be allowed to undertake the LKD risks. Performing this evaluation is particularly important for doctors who have a moral and professional obligation to uphold their ethics of non-maleficence with regard to the person who is to become a patient in virtue of donating a kidney. In addition, the donor's medical evaluations offer vital information regarding the donor's LKD-related risks. Moreover, if the prospective donor is deemed medically and psychosocially eligible to donate—i.e., if the person satisfies the relevant criteria—then the ensuing informed consent process needs to include information about health risks that is gleaned from the medical evaluation. Performing the donor evaluation to establish the acceptability of the donor is ethically justified for the purposes of protecting the safety, interest and well-being of the donor; supplying information to fulfill the disclosure requirement of informed consent; and allowing medical professionals to fulfill their fiduciary duty to the donor by preventing unjustifiable harm [17].

Another justification for performing a medical evaluation of the donor is for the protection of the recipient. Since a LDKT involves the implantation of the donor's kidney into the recipient, the transplantation could potentially be a medium for transmitting malignancies and infections, if any, from the donor to the recipient [12]. A thorough medical evaluation can help rule out such risk for the protection of the recipient.

The psychosocial evaluation should not be narrowly construed as an instrument for excluding unsuitable donors. Instead, the evaluation should highlight avenues for interventions to increase the positive outcomes of the LKD and to reduce any negative ones [13]. For example, it can identify donors who may require referrals for financial assistance in order to facilitate the LKD and mitigate the financial impact of the donation. In Singapore, donors who are citizens and permanent residents can apply for financial aid if the donor and recipient are unable to bear the cost of the LKD. The psychosocial evaluation of the donor is ethically justified, primarily, because it seeks to safeguard the well-being of the donor. Further, the psychosocial evaluation seeks to determine if the LKD decision is indeed voluntary—i.e., made without undue influence or coercion—and made with adequate understanding [8, 13]. In this regard, the psychosocial evaluation serves some of the same goals served by the informed consent process—as ensuring comprehension and voluntariness is part of the informed consent—however, the psychosocial evaluation does not involve obtaining the donor's informed consent. Not only is this a duty of the doctors, but also it can be carried out only when the donor has met the medical and psychosocial eligibility for LKD, is authorized by TEC for LKD and is willing to proceed with the LKD. Nevertheless, the psychosocial evaluation, much like the medical evaluation, identifies features of the donor's circumstances that constitute risks and benefits that must be weighed during informed consent. Finally, the psychosocial evaluation involves

gathering information pertinent to establishing that the donor is competent to give informed consent to donation.

The evaluations also serve to protect the integrity of the LKD process, for example, by helping to detect evidence of organ sales, which are prohibited. The psychosocial evaluation explores the donor's expectations and motivations for LKD and attempts to rule out donors who seek financial gain or are party to organ trading.

### **3.0 ETHICAL CHALLENGES IN LKD**

LKD presents particular ethical complexities, and evaluation of donors and determination of the permissibility of particular cases of LKD must take these complexities into account. In spite of the ethical challenges, as a practice, LKD remains ethically justified. The challenges do, however, suggest particular points that must be addressed during the donor evaluation process.

One ethical complexity in LKD concerns the risks and benefits of the intervention. LKD involves the donor incurring medical and health-related risks for the health-related benefit of another, the recipient. At the same time, the donor also seeks benefits through donation—which are of a psychosocial nature and which may or may not be realized. The precise nature, magnitude, and probability of such benefits depends on both contextual features of the particular situation and on the donor's own values.

Second, decisions to donate in the case of related LKD are driven largely, if not primarily, by donors' values, and especially in related donation by affections, emotions, and the relationship bond, not merely by medical facts of risks and benefits. In the case of unrelated LKD, it is the donor's interest in furthering particular values (e.g., altruism) and non-medical interests (e.g., enhanced self-esteem) that may drive decisions to donate.

Third, decisions to become a living kidney donor do not follow the contours of ordinary medical decision making either conceptually or practically [22]. A different constellation of considerations tend to influence decisions to donate, rather than self-regarding health-related interests that are prominent in other medical decisions. Others' interests may play a larger role

in the decision to donate than in other medical decision making contexts. Moreover, donors are reported frequently to make immediate, non-deliberative decisions to donate, to feel pressure to do so, and to consider such feelings of pressure to be normal or appropriate responses. [23].

Fourth, it is necessary to consider what limits on the autonomy of donors may appropriately be imposed either to protect their well-being or to protect the integrity of medical professionals who must operate on them, or both.

This chapter has four sections. Section 3.1 provides an overview of the cost, risks, harm and benefits of LKD. Section 3.2 considers the question of what limits on autonomy may be justifiably imposed for these reasons. Section 3.3 considers how donors have been found to make their decisions to donate, and the relevance of these findings for understanding autonomy and the requirements of informed consent in the LKD context. Section 3.4 then develops an ethical framework for the psychosocial evaluation of donors in light of these previously analyzed ethical challenges surrounding the practice of LKD.

### **3.1 THE BALANCE OF RISKS AND POTENTIAL BENEFITS IN LKD**

Despite the reassuring evidence that LKD is a relatively low risk medical procedure [5, 7], it poses prima facie ethical concern because harm is done to the donor through a nephrectomy—the removal of a kidney—with no direct medical or physical benefit to the donor who suffers irreversible, permanent loss of a healthy kidney in order to benefit the recipient. The donor has to live with a surgical scar, a permanent reminder of a kidney loss. More recent qualitative studies have reported post-LKD experience of bodily pain which was unanticipated by doctors, hence the donors were not primed beforehand and did not feel prepared when confronted with the situation [24]. Living kidney donors are known to face potential long-term risk for

hypertension, proteinuria and kidney impairment [20, 25]. There are concerns about a possible future manifestation of heredity risks for end stage renal disease in donors who have a first-degree relation to the recipients [26, 27]. To mitigate the problem of organ shortage, there is a growing trend in the U.S. to permit living donors with pre-existing controlled hypertension or low-grade proteinuria—conditions previously deemed as contra-indications for donor candidacy [20, 31]. Some 25 percent of living kidney donors have risk factors for future kidney disease, and are referred to as “medically complex donors” [32]. At least one study raised concerns about the rate of patients with obesity and proteinuria being accepted as living kidney donors in the USA [28]. A survey of 132 kidney transplant programs in the USA found that one-fifth determined 65 as the upper age limit for LKD, while 59 percent no longer placed an upper limit on age [20]. In some programs, donors above the age of 70 are now considered for donation [20, 21]. Singapore had its first geriatric living kidney donor in 2010 when a 75-year-old mother donated a kidney to her daughter [29], suggesting more leniency in its donor criteria than it once did. That safety and well-being of living donors may be compromised to increase the supply of kidneys for transplantation is a matter of ongoing concern.

Because transplant programs differ with regard to the medical criteria for a donor’s suitability, as well as their program-specific statistics regarding success, failure, and complications in transplantation, the same donor could receive different risk exposure at different programs. Donor safety, or the level of risk a donor faces, is affected by a transplant program’s selection criteria, experience and expertise. Most transplant centers in the U.S. do not track long-term outcomes of kidney donors [21]; the United Network for Organ Sharing (UNOS) requires transplant programs to report donor’s post-operative medical information only up to 24

months post-nephrectomy. Outcome data on various types of kidney donor remain scanty [20], which limits our understanding on the associated medical and long-term risks.

In evaluating the risks faced by kidney donors, the psychosocial impact of LKD must also be considered. Donors' post-donation experience of emotional and mental health issues has been reported, including depression, acute psychosis, and despair [30]. They can also be negatively affected by the recipient's death or graft failure [31].

In the case of unrelated kidney donors, because the donor is a stranger with no pre-existing relationship with the recipient, concerns arise regarding the psychological state and genuine motivations of the donor [32]. In comparison with intra-familial LKDs, where the donor and the recipient would have overlapping social support networks and therefore can share such mutual support, unrelated living kidney donors do not have this avenue to tap from and must solicit support from their own sources. Some studies suggest that unrelated kidney donors might be thought to have a less favorable psychosocial risk to benefit ratio when compared to donors who are related to the recipients, because unrelated donors lack the potential psychological benefit associated with benefitting someone with whom they have a relationship and/or preserving an important relationship [16, 33, 34]. However, such a view overlooks that an unrelated donor may enjoy a psychological benefit from giving selflessly that equals or exceeds the psychosocial benefits of a sibling-to-sibling LKD. Perhaps it would be more appropriate to state that society has greater understanding of the benefits a related donor would enjoy and is skeptical of the benefits an unrelated donor can derive from the LKD, hence explaining a greater acceptance for related than unrelated LKD. Yet, we should appreciate that there may be individuals who have a strong desire to be altruistic, or for whom altruism is an extremely deeply held value—or individuals who strongly desire to be heroic or for whom their self-esteem

resides in their being either very altruistic or heroic—being an unrelated donor may have great potential benefit. Thus, the risk to benefit ratio is very dependent on the circumstances and values of the individual donor, whether related or unrelated. Particularly if fulfillment of the primary value or goal of the donor rests with the act of donation—not the response of others, such as gratitude or increased social regard—then there is a good chance that the anticipated psychological benefit will be realized by the donor, whether related or unrelated. Unfortunately the paucity of studies on unrelated donors group limits our understanding of the nature and degree of psychosocial impact of LKD by unrelated donors [35].

Finally, the economic cost of LKD has to be considered as well. A systematic review indicated that living donors incur extra personal medical costs, such as hospitalization and pain medication, travel and accommodation expenses, personal care or home help services in the immediate post-operative period, and temporary loss of income associated with time taken for undergoing and recovering from the nephrectomy [36]. Donors can experience difficulty obtaining health insurance post-LKD [13, 31].

The cost, risks and harm inherent in LKD create an ethical challenge for doctors whose professional ethics require them to do no harm to patients, or non-maleficence. Of course, a surgeon would always do some harm to a patient—cutting into the body and leaving a scar—but this harm is outweighed by the anticipated therapeutic benefit of the surgery. The problem in the case of the physical and health-related harm done to a donor is that there is no counterveiling therapeutic benefit to the donor. The anticipated therapeutic benefit is to another, the recipient, while the donor suffers the harm and assumes the health-related risks for the sake of psychosocial benefit.

Therefore, we need to consider other harms, which if averted constitute potential benefits of donation, as well as additional potential benefits of donation in order to evaluate the risk to benefit ratio of LKD. First, we must consider the harm that may result from being prevented to exercise an autonomous decision to donate [16], for example, the anguish, grief, and guilt a loved one would feel if not allowed to donate a kidney despite being fit to do so. Second, we need to recognize that the donor is not acting entirely for the benefit of the recipient but also stands to receive psychological benefit from the donation [37, 38]. For instance, a parent-to-child LKD ends the parent's sense of helplessness concomitant with witnessing one's child endure a dialysis-dependent life while providing the parent a sense of self-worth for his/her ability to mitigate the child's suffering. The parent, along with the child and other members of the family, gets to enjoy solidarity and continuity as a family unit. Donors have also reported benefits such as improved donor-recipient relationship, enhanced self-esteem and self-concept [31, 38]. Even the belief that the recipient will benefit from the LKD may afford psychological and emotional benefits to the donor and this has to be considered as part of the evaluation. The opportunity to act altruistically through an LKD can also offer psychological and emotional benefits to the donor. Finally, individuals have an interest in having their autonomous wishes respected, and this benefit should not be overlooked or minimized in striving to protect the donor from harm. When we add the benefits of the LKD to its cost and harm, we attain a more accurate depiction of its risk to benefit ratio.

As the next section elaborates, what is at issue is whose weighing of risks and benefits and whose judgment of what is an acceptable or unacceptable harm, or an acceptable or undue risk, should govern whether a person desiring to donate should be allowed to do so. What constitutes harm is open to question, and acceptable or minimal harm does not mean no harm.

One reason for the medical and psychosocial evaluation of prospective donors is to help to ensure the relative safety of the procedure for them. Only medically acceptable candidates should become living kidney donors. They must be medically acceptable both in the sense of being suitable matches for the prospective recipient, and in the sense that donation will not present an exceptional or undue medical or physical risk to them. The donor must also demonstrate psychosocial suitability in that the psychosocial benefits of LKD will not be outweighed by its cost, risks or harm.

### **3.2 LIMITING DONOR AUTONOMY TO PROTECT THEM AND THE INTEGRITY OF THE MEDICAL PROFESSIONALS**

Because physicians commonly accept individual patients' personal, idiosyncratic weighing of the risks and benefits to them of medical interventions, and because these risks and benefits are recognized to include not only physical and health-related, but also psychosocial and quality of life-related risks and benefits, it is reasonable for physicians, in principle, to accept donors' decisions to donate. However, patient autonomy is not absolute; doctors have a professional and moral duty to protect their patients from avoidable medical risks that are not counterbalanced by expected benefits. Respecting patient autonomy, and allowing a patient to act on his/her decision, even when it entails unreasonable and unacceptable risks implies reducing doctors to being mere instruments of their patients' wishes. There may be some levels of risk that physicians may not allow patients to assume—either for the sake of their own hoped-for benefit (e.g., a very risky surgery with remote chance of success and benefit), or for the sake of others or psychological benefit. Physicians do have professional obligations to avoid unnecessary or unjustifiable risks to patients, and some potential cases of LKD may have a sufficiently

unfavorable risk to benefit ratio that a physician is justified in refusing to be complicit in a donor's voluntary assumption of such risks, even while generally endorsing the practice of LKD that balances donor autonomy, donors' subjective judgment of their interests, and physician obligations of non-maleficence by minimizing risks to donors while permitting them to act on deeply held values and desires [39].

At the same time, it is important to evaluate the phenomenon that unrelated donors' autonomous decisions are more likely to be overridden than those of related donors since if the medical and health-related risks they face are similar, it is believed that unrelated donors stand to benefit less from the donation when compared to related donors because of the absence of relational or emotional proximity [23, 40]. Transplant centers in the U.S. have been found to exercise more flexibility for donor consideration based on the donor-recipient emotional proximity [20]. That not all transplant programs in the USA accept unrelated donors is suggestive both of how they judge the unrelated donors' risk to benefit ratio and of support for limiting donors' risks. Unlike related LKD where the donor can be involved in the recipient's recovery—which proffers psychological and emotional benefits—the unrelated donor is denied such an experience out of consideration for the recipient's privacy. Similarly, unrelated donors are assumed to suffer less if their decision to donate is refused, as there is no specific relationship that may be disrupted by the death of a particular potential recipient, and there is assumed to be no risk of grief or guilt. Frustrated goals or disappointed desires are assumed to be less weighty than grief over loss of a loved one or frustration of the desire to help a specific other.

While it seems appropriate that the proportionality or risk-benefit ration should be evaluated in the context of inherent roles and responsibilities existing in the donor-recipient ties [37, 39, 41], it would also be ethically appropriate to evaluate the risk-benefit ratio for unrelated

donors in light of the nature and strength of their desire to donate. The probability and magnitude of this potential benefit to unrelated donors should not be underestimated [38, 42-44] yet the paucity of data available on their motivations and psychological and emotional benefits from unrelated LKD [45] make the evaluation of unrelated donors' decisions more challenging. As stated before, it is more accurate to recognize that there is greater social consensus surrounding the potential benefits to related donors and thus more social support for finding acceptable the risk to benefit ratio faced by related donors. Consensus views regarding the magnitude of risks and potential benefit, however, do not provide grounds for overriding donors' autonomous decision making when it is recognized that it is the individual donor's valuing of potential outcomes that should be taken into account when judging whether the risk of LKD is acceptable or whether the physician is warranted in overriding the donor's autonomy.

### **3.3 AUTONOMY AND INFORMED CONSENT IN LKD DECISION MAKING**

Respect for a patient's autonomy is the foundation of informed consent. Autonomy can be defined as a person's right and capacity for self-rule or to make free choices according to one's values and beliefs [46]. For an action to be autonomous, it must be carried out with intentionality, with understanding and without controlling influences. Both understanding and absence of controlling influence exist along a continuum; that is, they are matters of degree. In the context of LKD, both components—comprehension and substantial non-control—present some challenges for the conceptualization and evaluation of donors' decision making [46]. Each is discussed in turn following an overview of how donors are reported to make decisions.

### **3.3.1 Donors' Decision Making and the Substantial Non-control Requirement of Informed Consent**

LKDs are often between related people—whether biologically or emotionally related—and intra-familial donations are most prevalent. Since many donors report making the decision to donate without deliberation about the decision and indeed report feeling that they have no choice, related LKD has been considered to raise the question of whether such donations can be autonomous [30, 41, 47]. In one study, about 40 percent of the donors reported that their LKD decisions were not entirely voluntary and/or that they felt pressured by people or circumstances to donate [48]. However, feeling compelled to act in the interest of our loved one does not imply that we are no longer autonomous agents for one could still choose not to act for the benefit of those that one loves [37]. It must also be considered that being prevented from donating to one's loved one on the assumption of a lack of voluntariness associated with "role-imputed obligations" can be more distressing than the feeling of compulsion to donate. A feeling of compulsion upon reflection may be considered a motivation for action. An individual with excessive weight problem may feel compelled to start exercising and observing a healthy diet in order to avoid further medical and physical debilitations, but it does not necessarily mean that this person is unwilling or has reservations about observing a healthy lifestyle. Moreover, donors may not experience external pressure to donate and can be prompted by a desire to help others [49].

Because decisions to donate are made chiefly for the benefit of the recipient, we need to deviate from the traditional perspective on individual autonomy and impartiality where the individual is construed as an individualistic, free moral agent, and instead embrace a conception of the decision maker articulated within an ethics of care, as Kane and colleagues suggest [50].

An ethics of care 1) focuses on concrete and contextual elements instead of abstract principles, 2) aims to promote and sustain relationships by meeting the needs of people who are connected through their relationships, and 3) views people in their relatedness to others rather than as individualistic entities. Biller-Andorno [19] echoes a similar perspective when proposing adoption of a “relational model of the autonomous donor” where individuals are viewed as moral agents who, as relational beings, are still capable of autonomous choices. Individuals are spurred to act for the members in their family and social network because of the bonds they have, and these bonds are not to be perceived as bondage. To view familial obligations as unduly burdensome is to negate the reality of our existence as relational members of a family and to fail to recognize that such emotional bonds proffer benefits to be enjoyed just as they can place burdens to be carried [37]. Shouldering some burdens for another family member is not necessarily unpleasantly burdensome and on the contrary, may afford to the individual the benefits of family membership and may even bring pleasure. Similarly, the naturalness of the “non-choice” parents feel in deciding to donate should not be construed as a lack of freedom or autonomy, as undue pressure to donate to their offspring or as ethically problematic [47]. Instead, we should view the donation as an acceptable response of a parent spurred by his/her affection, devotion, commitment, relationship with and responsibility to the child. Parental and other intra-familial decisions to donate reflect the value individuals find in acting as relational beings who consider their emotional ties, roles and responsibilities when making moral decisions. In fact, while parents who are donors felt the most pressure to donate, they also experience the least ambivalence about donating [51].

To advance the argument differently, if the concern that intra-familial donors donate because they are compelled by their kinship bond, and that their decisions are therefore not

voluntary or substantially non-controlled because of the external or internal pressure and influence, it implies that only a disinterested party, such as a stranger, has no pressure and qualifies to donate [37]. It would then seem ludicrous that a family member cannot be allowed to sacrifice for his/her loved one and must await a stranger to act. In fact, there is greater acceptance by the transplant community and the society of related LKD than unrelated LKD, thus suggesting a general acceptance, if not expectation, that people donate a kidney and perform sacrificial acts on account of kinship and role obligations. Affections, emotions, and intimacy drive LKD decisions. Crouch and Elliot [37] aptly defended: “If we are ever to get straight about the nature of voluntariness, we must recognize that moral and emotional commitments are not exceptional, are not constraints on freedom, but are rather a part of ordinary human life” (p.38). The nature of related LKD compels us to deviate from a narrow notion of individual autonomy to that of a relational concept of autonomy. This perspective values human beings as individuals connected in a web of relationships, and recognizes how relationships can drive decisions and motivations in life.

### **3.3.2 Donors’ Decision Making and the Requirements of Comprehension and Deliberation**

Besides questions of the voluntariness of donors’ decisions, the other related concern, identified especially with parental kidney donors, is the spontaneity or lack of deliberation with which such decisions are made, before full information disclosure by medical professionals. In a pioneering study on living kidney donors, Fellner and Marshall [22] reported that donors decided on donating a kidney from as early as receiving news of their loved one’s illness and need for a kidney transplant [22]. Their decision was made even before they were presented the medical

facts regarding LKD and LDKT and pertinent recipient's LDKT-related information. Various subsequent studies corroborate this phenomenon, prevalent particularly in parent-child LKD [30, 39, 48, 52-54]. For example, in examining the degree of understanding and voluntariness among 262 living donors, Valapour and his colleagues [48] found that while 90 percent of donors understood the effect of LKD on recipient outcome, only 69 percent understood the psychological, long-term medical and financial costs of their LKD. Their donation decision was influenced only by their understanding of possible recipient outcomes and their emotions and values. The immediacy of the donors' decision and their minimization of medical facts potentially compromise their comprehension of the risks of LKD and their consideration for self-interest, which in turn leads to concern about whether the requirements for informed consent can be met [39].

To insist, however, that decisions are to be made only after achieving material understanding from discussions with doctors falsely assumes either that patients do not possess prior medical information of their own, or that their decisions should be made primarily based upon such medical or health-related information. This view is also an imposition of a particular value-laden view that decision making processes should follow a particular pattern, which undermines respect for both donor autonomy and value pluralism. Instead, adequate understanding may be achieved in many ways; disclosure during patient education and informed consent is only one avenue. Faden and Beauchamp [46] state, "so long as the understanding is substantial, it makes no difference whether this understanding is self-taught, reflects prior experiences and history, is derived from a video tape..." (p. 305). As long as the donor comes to understand the risks and benefits of LKD and LDKT, as well as the recipient's treatment options, this level of understanding should be considered to meet the informed consent requirement for

material understanding [47]. To invalidate a donor's decision because of its immediacy or the likelihood that is made prior to considering the associated risks—or because the decision is based on emotions more than on rational weighing of risks and potential benefits—would be to ignore the reality and importance of relationships to individuals and how such relationships can influence LKD decision making [50].

Moreover, in the context of LKD, emotions and features of relationship actually constitute some of the risks and potential benefits of LKD. It may be, for example, a desire to restore a relationship with the recipient, for example, that constitutes the primary potential benefit of donation for a prospective donor. At the same time, the possibility that the relationship will not be restored (either because the recipient dies, or because he does not appreciate the donation and restore the relationship) then constitutes the primary psychosocial risk. The process of informed consent and the evaluation of the donor's decision must take into account the nature of the risks and potential benefits donors incur.

Similarly, unrelated donors could be so eager to donate, perhaps because they hope to achieve enhanced social standing for their heroic contribution or because they believe they will enjoy enhanced self-esteem (apart from others' responses to their donation)—that they may not adequately comprehend the information disclosed to them about LKD or accurately weigh the risks and potential benefits. In comparison to studies of related donors, there has been less study of how unrelated donors' altruistic desires and other motives for donation affect their ability to give valid informed consent. In the absence of legally prohibited financial incentives for donation, a market in organs, or obviously illegal (and unethical) coercion, unrelated donors are less likely than related donors to suffer from undue external pressures. Whether their extreme altruism or desires for enhanced social recognition or self-esteem constitute—or border on

constituting—psychological pathologies and thus undue internal pressures may be explored in the psychosocial evaluation process.

Finally, the medical and psychosocial evaluations of the donor provide safeguards that serve to prevent donors from proceeding with the donation if the risks in a particular instance of LKD are significant or disproportionate to the benefits, or if the donor’s comprehension of LKD is significantly inadequate. In addition, the donor evaluation process affords an opportunity for the donor’s acquisition of additional information, achievement of material understanding of the risks and potential benefits and reflection upon the “fit” between the decision to donate and the donor’s values, circumstances and life plans.

### **3.4 ETHICAL FRAMEWORK FOR THE PSYCHOSOCIAL EVALUATION OF THE LIVING KIDNEY DONOR**

Table 1 presents the information gathered in a typical donor psychosocial evaluation in Singapore. This includes the donor’s: 1) demographic information, 2) employment and financial information; 3) family composition, roles and dynamics, social support system; 4) lifestyle issues; 5) psychological and psychiatric issues; 6) relationship with recipient; 7) motivations to donate; 8) comprehension of LKD; 9) voluntariness regarding the decision to donate; and 10) competence [8, 13, 16-18, 55]. These domains provide a comprehensive perspective of the donor in relation to the LKD decision, and highlight the factors that can affect the risks and potential benefits of LKD for particular candidate donors, as well as LDKT medical outcomes. Information obtained from such evaluations allows the transplant team to assess the psychosocial fitness of the donor for an LKD. Such protocols can function as procedural safeguards [19].

The complex nature of LKD makes it impossible to stipulate a quantifiable threshold and global scale for each psychosocial evaluation domain. The myriad of related donor-recipient relationships and their complexities compounds this difficulty. However, relying on an ethical framework to inform application of the criteria in each evaluation domain can help. The overarching ethical principles of non-maleficence, autonomy and justice can provide guidance regarding what would constitute reasonable criteria for LKD [23, 39, 41, 56-58]. Relying on an ethical framework to apply and interpret the criteria has the additional advantage of offering breadth and flexibility to allow for a case-by-case consideration that addresses the individual complexities of particular candidate donors. For example, a pair of siblings from Brunei is seeking LDKT in Singapore—fully paid by the government of Brunei—because their country does not offer this service. The social worker evaluating the case would have difficulty ascertaining what minimum amount of financial resources that the donor has would be adequate to buffer the donor from any LKD-related financial impact because they are foreigners from a country with a standard and cost of living different from Singapore. Even if this information were readily available, it would not be as important as information pertaining to other domains of the psychosocial evaluation—such as the motivation for and voluntariness in donation—because the financial cost of LKD and LKDT are taken care of by the government. Another reason to employ this ethical framework to apply psychosocial criteria in individual cases is that the data on the association between psychosocial risk factors and transplant outcomes remain inconclusive, thus precluding the availability of a standardized and quantifiable psychosocial assessment tool [16, 45]. Further, there is no universal risk-benefit ratio associated with LKD; instead, the risk-benefit ratio must be evaluated from the individual donor’s perspective in light of the individual’s particular medical and social circumstances and these will be difficult to

quantify using psychosocial criteria. Finally, the ethical framework that grounds the psychosocial evaluation criteria and their application is the same framework that grounds the requirement for informed consent.

The psychosocial evaluation of prospective donors should therefore involve both psychosocial and ethical considerations. For an ethically-appropriate LKD: 1) the potential benefits must outweigh the harm for the donor; 2) the donor must have adequate understanding of LKD, including its risks and potential benefits; 3) the donor must have realistic expectations regarding what the LKD can achieve; and 4) the donor's decision to donate must be voluntary. Evaluations must consider the situational context, including its impact on the potential donor as well as the recipient [37]. It is important to note that although information gleaned from a psychosocial evaluation can lend some understanding of whether and how the ethical requirements for donation (e.g., the requirements of informed consent) are met, the social worker performing the psychosocial evaluation should not be making an ethical evaluation of the prospective donor, nor should she/he be evaluating the ethical acceptability of the proposed LKD. This clarification and distinction of the social worker's role is important. HOTA refers to the social worker's psychosocial report as an "expert review" for the TEC to rely on, and stipulates that the social worker is to highlight any ethical concerns to the TEC. However, according to the directives established by the HOTA, the social worker should confine his/her assessment to identifying, evaluating, and reporting the psychosocial aspects of the case, which admittedly include ethically relevant findings, but should not weigh the ethical appropriateness of donation in light of those findings. The TEC should be the one deciding on the ethical appropriateness of an LKD, hence the authorization to proceed or not should rest with the TEC, not the social worker. Not only does the law divide and allocate responsibilities in this manner,

but importantly, it does not vest a single person with the authority to decide whether a potential kidney donation should go forward. Requiring that this decision be made by a committee helps to reduce the possibility of individual bias unduly affecting the decision; ideally, in the committee's deliberations such biases may be identified and countered. Moreover, it avoids, to some degree, the error of the "generalization of expertise" [59] which might arise if a social worker with training and expertise in psychological and social evaluation were charged with making a decision instead requiring other training and expertise, perhaps including ethical expertise, as well as incorporation of other considerations beyond those regarding the donor's psychosocial circumstances and features.

**Table 1.** Ethical framework for the psychosocial evaluation of the living kidney donor

<b>Assessment Domains</b>	<b>Psychosocial Criteria</b>	<b>Normative Principles</b>
<b>I. Donor's demographic &amp; background information</b>		
Age	<p>Above 21 years of age</p> <p>The upper age limit is as indicated by the respective transplant center's policy. Increased age is associated with increased illness morbidity risk</p>	<p>To satisfy the minimum legal age for providing informed consent.</p> <p>Safeguard the well-being of the donor.</p>
Gender	<p>There is no undue pressure or coercion on female donors to donate because of culturally-linked gender bias.</p> <p>Internationally, more females than males serve as living donors [34, 60]. Exploration on possible social and family pressure faced by female donors to donate is important for establishing the voluntariness behind LKD decision [34, 61].</p>	<p>Safeguard the well-being of the female donors by ensuring that the donation is not made under culturally-imposed pressure.</p> <p>Ensure voluntariness in the decision of female donors to donate a kidney.</p>
Educational level	<p>No minimum education level is required. Although education level can affect health literacy, those who are illiterate or uneducated are capable of giving informed consent to complicated medical procedures. The requirement is for comprehension of the medical information presented, not a particular level of education.</p>	<p>The donor's comprehension of presented medical information is a requirement for informed consent, and donor's comprehension of what to expect during and after donation may aid recovery and protect well-being [13].</p>
Living Arrangement	<p>Arrangement can be made for a caregiver to be available to support the donor in post-nephrectomy recuperation.</p>	<p>Safeguard the well-being of donor</p>
Employment and financial information	<p>The donor should have steady employment or adequate financial resources that will not be unduly jeopardized by the LKD.</p> <p>The LKD should not lead to the donor losing his/her job and resulting in financial distress or hardship, nor should loss of a kidney render the donor to be incapable of continuing in his/her employment or to be particularly vulnerable to physical/medical risks of that employment.</p> <p>There should be adequacy of financial resources to support the donor through the LKD. Any significant out-of-pocket expenses related to</p>	<p>Minimize cost or risk to the donor.</p> <p>Safeguard the well-being of the donor.</p> <p>Promote well-being of the donor through avoiding unreasonable financial impact that the LKD may impose.</p>

Assessment Domains	Psychosocial Criteria	Normative Principles
	<p>LKD will not destabilize the donor’s financial situation.</p> <p>There should be absence of major financial stressors that may have coercive impact on LKD decision, or that may exacerbate post-LKD coping</p>	
<b>II. Family and social support system</b>		
<p>Family composition, roles and dynamics</p>	<p>In intra-familial donation cases, understanding the family composition, roles and dynamics can offer helpful interventions and avoid undue burdens on the donor or family. This understanding may:</p> <ol style="list-style-type: none"> <li>1. Place the donor and recipient in the context of the family structure and their relation to other family members who may be potential donors.</li> <li>2. Shed light on the roles and responsibilities of the donor with regard to his/her position in the family, and thus how LKD may temporarily disrupt execution of these roles and responsibilities.</li> <li>3. Potentially highlight “black sheep” role that the donor may have, or any guilt prompting the LKD decision, to redeem his/her position in the family or compensating for his/her past behavior.</li> <li>4. Identify undue pressure or influence from family members on the donor to donate a kidney.</li> <li>5. Identify potential caregiver(s) and support for the donors to cope with any multiplicity of his/ her roles in the family and that as a donor. For e.g. a donor who is also a caregiver and/or breadwinner in the family or to the recipient.</li> <li>6. Identify stressors/conflicts in family relationship that may influence and affect the LKD decision and outcome. There should not be multiple or significant family stressors that will be exacerbated by LKD. Presence of multiple family stressors and obligations are indication of higher psychosocial risk and may</li> </ol>	<p>Safeguard the well-being of the donor by minimizing cost and risk to the donor, including the burdens of familial conflict.</p> <p>Maximize benefits for the donor by bolstering support from the family.</p> <p>Uphold donor’s autonomy by placing his/her informed and voluntary decision regarding LKD above the opinions of the family.</p> <p>The donor’s decision to donate must be voluntary, i.e., not subject to substantial controlling influences.</p>

<b>Assessment Domains</b>	<b>Psychosocial Criteria</b>	<b>Normative Principles</b>
	<p>render a negative LKD outcome.</p> <p>Help family members comprehend donor’s LKD wishes and motivation, even though they do not necessarily accept the decision to donate.</p> <p>While support or absence of opposition from the donor’s significant other(s) regarding the LKD is not a prerequisite for LKD, their views are to be explored so that the potential impact of LKD can be better understood. If the LKD is to proceed without support from the spouse or significant other, the donor needs to understand and accept the potential impact of LKD on the relationship with spouse or the significant other.</p> <p>Intra-familial resistance to the donor’s decision may suggest the donor and/or family’s lack of understanding or unrealistic expectations for LKD which must be addressed.</p> <p>Culture-specific perspective and values on the roles of the individual and the family should be considered.</p> <p>Assuming that the cost or harm of LKD do not outweigh its benefits, the donor’s values and preferences donate are to be given greater weight than the values and preferences of others.</p>	
Social support system	<p>Adequacy of social support to aid the donor through the LKD process should be available. If adequate support is not available through the donor’s social network, then the feasibility of formal or community resources supplying such support can be determined and initiated when required.</p>	<p>Safeguard the well-being of the donor by minimizing cost and risk to the donor.</p> <p>Maximize benefits for the donor by connecting the donor to needed support or resources.</p> <p>By identifying sources of support outside of the family, justice is promoted by enabling less well-off families to participate in the process of donating and receiving a kidney. This life-saving and quality-of-life enhancing intervention is thereby not reserved for those who can afford the requisite supports. Further, donors who lack family members to supply such support are enabled to participate in LKD, reap the benefits of being altruistic and/or of protecting the well-being of someone about</p>

Assessment Domains	Psychosocial Criteria	Normative Principles
		whom they care (the recipient).
<b>III. Lifestyle issues</b>		
High risk sexual behavior	<p>High risk sexual behavior such as unprotected sex with multiple sex partners, purchase of commercial sex, or sexual engagement with people at risk of HIV, hepatitis B (HCB), or hepatitis C (HCV) may present health risks of transmission of disease via the donor organ [46].</p> <p>These behaviors must be evaluated in terms of the risk presented by a past history and the risks presented by continued or future participation in these behaviors.</p> <p>According to CDC, the following are exclusion criteria for organ donation [62]:</p> <ol style="list-style-type: none"> <li>1. Male donors who have had sex with other men in the preceding 5 years.</li> <li>2. Donors with nonmedical injection drug use in the preceding 5 years.</li> <li>3. Donors with hemophilia or related clotting disorders who have received human-derived clotting factor concentrates</li> <li>4. Donors who have engaged in sex in exchange for money or drugs in the preceding 5 years.</li> <li>5. Donors who have been exposed to or had sex in the preceding 12 months with a person known or suspected to have HIV, hepatitis B (HVB), hepatitis C (HCV) infection.</li> </ol>	Protect the well-being of the recipient by reducing risks of transmission of disease by means of transplantation.
History of drug abuse.	<p>Active drug abuse is a clear contraindication for LKD as it can exacerbate health risks of donation and impair donor’s decision-making ability.</p> <p>Some forms of substance use (e.g., injection drug use) increase the likelihood that the donor’s organ may present health risks to the recipient, so both past and current history of such use should be ascertained.</p> <p>Donors with a history of substance abuse should have a minimum six-month abstinence pre-LKD [18, 52, 55].</p>	<p>Safeguard the well-being of the donor by reducing risk.</p> <p>Protect the well-being of the recipient by reducing risks of transmission of disease by means of transplantation.</p>

Assessment Domains	Psychosocial Criteria	Normative Principles
<b>IV. Psychological and psychiatric issues</b>		
Psychological and psychiatric issues	<p>Undergoing an LKD can be a stressful event for some individuals [38], hence the concern that it may trigger a recurrence or increase risk of mental health problems. Psychological and psychiatric issues may impair the donor's 1) cognitive abilities, 2) reality appraisal and 3) comprehension of LKD and its risks and benefits, thus leading to unfavorable post-LKD outcomes. Substantial impairment may be contraindication for donation.</p> <p>Psychometric instruments [16, 17, 63] and mental health assessment by mental health providers can be utilized to assess the donor's psychological and psychiatric functioning. Substantial risk that a donor may not be able to deal with aspects or outcomes of the LKDT process must be included in determining the risk-benefit ratio of the proposed donation. The negative sequelae of not being allowed to donate should also be considered. The probability of outcomes that might trigger negative psychological response, as well as the probability and magnitude of those responses, should be considered.</p> <p>The information gathered here is not narrowly focused on ruling out the donor's candidacy but instead can be channeled to help the transplant team formulate plans for necessary support if the donation goes forward, so as to enhance the donor's post-LKD recovery [13].</p>	Safeguard the well-being of the donor.
History of self-harm or suicide attempt(s)	A history of past self-harm or suicide attempt(s) may suggest that the donor has poor emotional and psychosocial coping with stress and/or has poor social support and insight into problems and requires closer examination. The risk of recurrence of self-harm or suicidality should be minimal. While past suicidality should not be an absolute barrier to donation, because of the magnitude of harm involved—including impact on others (including the recipient) who may be affected if the donor were to attempt suicide—the probability of this risk should be low.	Safeguard the well-being of the donor.
Stress coping	Undergoing an LKD can be stressful and may aggravate the donor's	Safeguard the well-being of the donor.

<b>Assessment Domains</b>	<b>Psychosocial Criteria</b>	<b>Normative Principles</b>
	<p>current stress level and coping.</p> <p>The donor should have adequacy in coping with current stress, does not have maladaptive stress coping style and is able to handle LKD-related stress.</p> <p>Donor with multiple life stressors can be a high psychosocial risk, especially if not complemented with adequate support or resources.</p>	<p>Minimize the risk and cost to the donor by ensuring that the donor is able to cope with the stress of undergoing an LKD.</p>
<b>V. Donor-recipient relationship</b>		
<p>Nature of donor-recipient relationship</p>	<p>The nature of donor-recipient relationship can potentially influence the psychosocial risk-benefit ratio.</p> <p>The nature of donor-recipient relationship should not alter the degree of donor's risk taking.</p> <p>Relational proximity and emotional closeness are common significant motivators behind LKD. However, related donors, particularly intra-familial donors, may face undue influence, pressure or coercion to donate, thereby reducing the voluntariness of the decision to donate. This has to be ascertained.</p> <p>Emotionally-related LKDs should provide evidence of an existing emotional relationship between the donor and the recipient [8]. There should not be estranged or long-standing conflicts between the donor and recipient.</p> <p>Imbalance in power that places the donor at a subservient position to the recipient may increase the vulnerability of the donor to yield to pressure to donate; for e.g. an employer-employee relationship [8, 13, 14] .</p> <p>The following types of unrelated donors are considered higher psychosocial risk, requiring greater scrutiny:</p> <ul style="list-style-type: none"> <li>• Foreign nationals</li> <li>• Responders to Internet or media appeals</li> <li>• Donors motivated solely by religious beliefs</li> </ul>	<p>Safeguard the well-being of the donor.</p> <p>Minimize the risk to the donor by ensuring that the donor-recipient relationship is not exerting undue pressure, undue influence or coercion on the donor to donate a kidney.</p>

Assessment Domains	Psychosocial Criteria	Normative Principles
	<ul style="list-style-type: none"> <li>• Donors in paired or list-paired donation</li> <li>• Donors with a subservient relationship to the recipient (e.g. employee, student)</li> </ul>	
<b>VI. Motivation to donate and expectations of LKD</b>		
Motivation to donate	<p>The decision to donate should contain an altruistic element.</p> <p>Assessing the motivation of donors for LKD will help:</p> <ol style="list-style-type: none"> <li>1) evaluate aspects of informed consent such as voluntariness</li> <li>2) rule out donations that exclude altruism</li> <li>3) rule out donations that are financially-motivated. Expectation of financial reward for LKD is a contra-indication for donor candidacy, as this practice is prohibited by law.</li> </ol> <p>Issues such as presence of internal or external pressure to donate, expectations from the LKD and possible financial benefits to be expected or derived from the donation are to be explored. LKD should not be motivated by guilt, enticements, impulsive responses, and additionally in the case for related LKDs, attempts to repair or receive rewards in the donor's relationship with the recipient or the family, etc. as these may result in adverse psychological, emotional or relationship impact when the intended outcomes are not achieved. Further, such motivations undermine the altruistic nature that ought to characterize LKD.</p> <p>Unrelated LKDs should preferably be undirected.</p> <p>The absence of family and emotional ties in unrelated LKDs is believed to reduce the benefits the donor may enjoy, hence requiring greater scrutiny for the donor's donation motivations.</p> <p>In unrelated LKDs, a desire for recognition or publicity, and a wish for future relationship with the recipient are considered unacceptable motives because these goals not only are unlikely achievable but that they imply that the LKD is not altruistically motivated.</p> <p>It is important to note that some degree of ambivalence surrounding</p>	<p>Safeguard the well-being of the donor.</p> <p>Protect the integrity of the organ donation and transplantation system, as well as the public's confidence in it and its fairness by ensuring that LKD is based on appropriate motivations.</p> <p>Safeguard the donor's well-being and promote realistic understanding of the potential benefits of donation to enable informed consent.</p>

Assessment Domains	Psychosocial Criteria	Normative Principles
	LKD is normal. A donor's ambivalence or reservation does not imply that the donor is an unsuitable candidate. Instead it suggests a need for further exploration and understanding before determining if the donor is voluntary and able to proceed with LKD. Depending on the case, the LKD may be either deferred and the donor re-assessed at a later period for candidacy, or the donor is ruled out as a suitable candidate.	
<b>VII. Informed consent</b>		
Comprehension of LKD and pertinent medical information.	<p>The donor must receive, understand and be able to retain pertinent information regarding LKD.</p> <p>The donor should be able to understand and accept that the recipient's LKD outcome, whether positive or negative.</p> <p>Donor is to be informed why the recipient is eligible for a kidney transplant, the risks and benefits of LKD and the recipient's treatment alternatives.</p>	<p>Safeguard the donor's well-being by ensuring that the donor understands why he/she is donating a kidney and the risks and harm associated with the donation.</p> <p>Meet the comprehension requirement of informed consent.</p>
Voluntariness in the decision to donate	Absence of undue influence, pressure or coercion on the donor to donate should be ascertained.	Safeguard the well-being of the donor, as well as ensure that the voluntariness requirement of informed consent is met.
Competence	<p>The donor must have the decisional capacity to provide informed consent. The donor must be able to reason, deliberate and communicate the LKD decision.</p> <p>A limited decisional capacity is a contraindication for donation.</p>	Safeguard the well-being of the donor, as well as ensure that the competence requirement of informed consent is met.

#### **4.0 THE PSYCHOLOGICAL EVALUATION PROCESS**

Generally, the psychosocial evaluation process is to be performed by a party who is not involved in the care of the intended kidney recipient and who possesses mental health training [12, 13]. This is to allow an independent assessment of the donor to avoid conflict of interest. Prior to the evaluation, the social worker obtains medical information about the donor and the recipient in order to develop adequate understanding of their medical conditions and the medical risk-benefit ratio for LKDT.

The donor is encouraged to invite a “collateral person”—usually a significant other, a family member or the donor’s caregiver—to the evaluation session [15-17, 35]. Guidelines developed at a joint meeting of the United Network for Organ Sharing (UNOS), the American Society of Transplant Surgeons and the American Society of Transplantation recommend an interview or telephone call with the significant other of the unrelated donor [14]. The thesis will discuss the proposed role of the collateral person and the ethical concerns in section 4.1.

Typically, the session begins with an explanation to the donor and the collateral person (if one is involved) of the types of information to be gathered and objectives of the psychosocial evaluation. The latter are: 1) to ensure that the donor understands the impact and implication of the LKD decision, 2) to assess the donor’s adequacy of resources and support for LKD, 3) to ascertain that the LKD is entirely voluntary, and 4) to safeguard the physical, emotional and psychosocial well-being of the donor, including the donor’s interest in confidentiality and privacy. They are to be informed that to safeguard the prospective donor’s welfare, autonomy,

and privacy, the donor will be interviewed individually (i.e., separate from the collateral person) for part of the session, and that the evaluation may entail additional referrals, assessments and interventions. The social worker proceeds to gather information based on the assessment domains (refer to Table 1, page 29).

The social worker should be clear that the donor psychosocial evaluation is to determine the donor's psychosocial fitness to donate, and separate the evaluation from other social work functions aimed at increasing the positive outcome of the LKD. Such functions are to be deferred to after the donor has been accepted for LKD. The social worker should therefore explain to the donor that in the context of the psychosocial evaluation, the donor is not like the client in the usual social work context where the social worker intervenes and refers for required supportive services.

To ensure donor autonomy, the social worker should inform the donor that he/she retains the right to withdraw the intention to donate at any point prior to the surgery, and that the reason(s) for such a decision will remain undisclosed to the recipient unless the donor chooses to divulge [8, 13, 15-17, 55]. Maintaining the confidentiality of a donor's decision to withdraw is important so that the donor will not feel compelled to proceed with the surgery, which will otherwise compromise the voluntariness to donate and breach the requirements of informed consent. A decision to renege from the initial idea of a related LKD can potentially strain donor-recipient ties and which the donor may be unprepared to face, hence requesting help from the transplant program to offer a medical reason for donation unsuitability in order to graciously exit. Existing protocols mainly suggest a general statement of the donor's non-suitability to be offered to the recipient in the event that the donor withdraws the LKD decision [13, 16, 63]. I would suggest stating that the "donor candidate is not suitable for donation" should suffice since

a lack of voluntariness indeed disqualifies the donor from donating. However, to minimize such situations where a recipient presses for a reason for the donor's unsuitability, as a matter of practice, transplant programs should indicate at the onset of transplant evaluations that in the interest of donor confidentiality, no reasons will be provided to the recipient if the donor is found unsuitable to donate. Although this may prompt the recipient to channel the question directly to the donor, who may find the situation stressful or awkward to deal with, there are further ethical concerns with colluding with a donor who feels a need to develop a (false) medical excuse after all.

The Consensus Statement appears to support participation in deception and suggests supplying mild medical reasons such as "mild hypertension" or "blood glucose level" for the reason that a prospective donor is not eligible. At the same time, in a contradictory manner, it maintains that the donor's medical information should not be falsified to mask the donor's reason for withdrawal from LKD, as such fabrication, if documented, could risk the donor from successfully obtaining future life insurance or affect the donor's future health seeking or treatment [13]. A suggested alternative as a reason for a prospective donor's not proceeding with donation is to provide a medical disclaimer, for example, a human leukocyte antigen (HLA) mismatch [13], implying there is immunological incompatibility between the donor and recipient such that the donor must be ruled out for LKD.

However, the most ethical practice, and thus the appropriate policy, is to provide no reason or excuse for the prospective donor who withdraws or is withdrawn from (or following) evaluation. Instead, the social worker and healthcare professionals involved should explain that they are not at liberty to discuss the donor's private information and are only at liberty to confirm that the person is no longer a potential donor. To collude with a withdrawn/withdrawing donor

in deception is inappropriate for several reasons. First, truth-telling is an important ethical value in medicine and social life more generally. Second, to be found to have participated in deception could justifiably undermine confidence in the veracity of other information disclosed by the transplant team and/or social worker, and undermine trust in the transplantation process and in the healthcare system more generally. Imagine that a second prospective donor, who is found suitable during medical and psychosocial evaluations and who then consents to donate, then discovers that the social worker (or other healthcare professional involved in the transplantation process) has lied or colluded in deception regarding the reason for the previous prospective donor not being a suitable candidate. This second donor now has reason to question the veracity of information disclosed during the patient education and informed consent processes. Finally, to embrace or lend weight to the perception that it is appropriate for others to seek a medical reason for the donor to withdraw/be withdrawn, by agreeing to participate in such a deception, serves to undermine support for the right of the prospective donor to refuse donation for any reason at all. Rather than agreeing to participate in such a deception, the social worker (and other professionals involved in the transplantation process) should emphasize that what is important is the right of the donor to decide and that what is important for the professionals to do is to support that decision with the truth. After all, a person who does not want to donate is not an eligible donor. Always giving the reason that “X is not an eligible donor” and no more explanation fulfills the ethical obligation of truth-telling and treats all ineligible donors the same way in this regard, thereby protecting the privacy of all of them and treating them fairly. The transplant program can, if requested by the donor (now more appropriately referred to as the “withdrawn-donor”) inform the recipient that the donor is no longer a suitable candidate, but the

program should state that it is not appropriate to discuss the circumstances of (in)eligibility further due to considerations of the withdrawn-donor's privacy.

Some protocols recommend a "cooling off period" between the donor's consent and the surgery [13, 17]. Under HOTA, a minimum seven days cooling period is required between the TEC authorization and the surgery to provide the donor "the opportunity to reflect upon, and reconsider his decision if wished, as well as to clarify any doubts or concerns with the transplant physician(s)" [8]. The situation can become complicated if after the TEC's authorization for LKD has been given and the donor changes his/her mind during the cooling period or just at the point before the surgery is about to take place, and asks for help from the transplant program to gracefully exit from the LKD offer. Therefore, the donor who is approved should be advised not to reveal this approval during this period if there is any possibility that he/she will decide to withdraw. Once the TEC's authorization has been given, it would no longer be feasible for the donor to employ a (false) medical excuse because at this advanced stage, any medical contraindication for LKD will have been ruled out. It is always up to the donor to decide if he/she wants to offer any reason for why the LKD cannot proceed as planned. These proposed steps are to safeguard the donor's confidentiality. The donor and recipient should be supported to cope with the impact of non-donation, if necessary.

Cross-cultural issues and the language compatibility and language proficiency of the social worker and interviewee must be considered prior to the interview. Where necessary, an interpreter should be used in order to ensure adequate understanding of the communicated material. This is important for meeting the requirements of informed consent whereby the donor must attain a reasonable level of understanding regarding LKD, its impact and implications. In Singapore where bilingualism and multi-lingualism are common, hospital services do not engage

professional interpreters for the main languages used in Singapore (i.e. English, Mandarin, Malay and Tamil) but rely on available healthcare providers for interpretation where needed. A donor's family member should not perform the interpretation so as to protect the donor's privacy, avoid bias and conflict of interest, and allow the donor a safe environment to freely express his/her LKD-related concerns [13, 17]. It is important that those providing interpretation are informed about and abide by the rules of patient confidentiality.

#### **4.1 INVOLVEMENT OF A COLLATERAL PERSON**

Several psychosocial evaluation protocols recommend the involvement of the donor's "support person" or "significant other" [14, 16, 17, 55, 64], also referred to as "collateral person" in the interview. However, the role of this collateral person has not been clearly and consistently defined. HOTA requires the involvement of a "third person" as part of the evaluation process as described below [8].

1. In emotionally-related LKD, the burden of proof of an established emotional relationship is on the donor and the recipient".
2. "All emotional relationships should be considered valid for donation only if they are verifiable through and corroborated by independent parties (e.g. interview with a shared family member, interview with a shared friend, etc.) and/or relevant documentation (supporting documents could include legal documents showing the relationship, a certified statement from the recipient's and donor's common employer where the donor-recipient relationship is that of a long-time colleagues, etc.)."
3. There is "proof that the donor's immediate family members (parents and spouse) have been informed of donor's decision (objections by a living donor's family does not automatically

disqualify the potential donor, but these objections should be taken into consideration in the evaluation of the donor's motivation).”

4. The TEC has “the authority to query the authenticity of the documents or information presented to them and request additional supporting documents, including but not limited to statutory declarations and additional interviews...and includes repeated interviews...even with a third person to reaffirm the donor's willingness to donate his organ.”

Based on the above stipulations, the following assumptions may be drawn from HOTA. HOTA's requirement that the donor's immediate family be informed of the LKD reflects Singapore's societal and cultural value where regard for the family, not just the individual autonomy, is valued. For the dominant Chinese race, the cultural value of familism views the family as a collective entity of individual family members where seeking the views of the pertinent family members is culturally appropriate, and often construed as necessary. The central role of the family in an individual's life is reflected in various policies. For example, the immediate family (defined as parents, children and spouse) is expected to offer financial support and physical care to the individual; in healthcare financing policies, the family is required to utilize their Medisave—a national medical savings account—for their loved ones' medical expenses; and the Tribunal for the Maintenance of Parents Act allows parents to file for a maintenance order against their children who are not supporting them financially. Housing policies are crafted to promote the position of the family in the individual's life by providing incentives for family members living together or close by. The family is looked upon as the first line of support for the individual and naturally the first system to experience and bear the consequence of an individual's decision. Therefore, it is often assumed that just as family has the responsibility to provide and care for its members, it has the rights to be apprised of—which

does not equate with any rights to influence or interfere in—its members’ decision-making process. In the case of LKD, because of the likelihood that the donor’s family will be involved or impacted in varying degrees, for example, by providing the donor post-LKD care, the acceptable cultural practice—as seemingly interpreted by HOTA—is to engage the family as collateral persons.

HOTA appears to assume the views conveyed in some evaluation protocols that the involvement of a collateral person can be beneficial to the donor’s LKD decision making by eliciting their views. For example, one protocol holds that the collateral person may be able to offer opinions that can help balance the donor’s perspective on the LKD and address the donor’s needs that may have been overlooked in the donor’s earnestness to donate [65]. Another protocol suggests that having a collateral person may bring to the surface any disparate views or conflicts between the donor and the collateral person regarding the LKD decision, thus paving a need for further exploration by the evaluator to determine underlying issues that may require intervention [16].

Also, based on the historical context preceding the Amendments to HOTA pertaining to living donor donation and transplantation, it would be reasonable to infer that the stipulations in HOTA are intended as safeguards against organ trade where impoverished foreigners present as emotionally-related donors claiming an LKD prompted by emotional bond and altruism, hence its emphasis on documentation and corroborations to prove the authenticity of information and the nature of donor-recipient relationship. The language of HOTA therefore inclines towards an assumption that a donor may be biased, selective in information disclosure or lying, which in turn is assume to warrant the need for collateral person’s corroboration. Or HOTA may be interpreted to assume that the donor is ignorant or ill-informed, thus necessitating the

involvement of the family collateral person who can supply information to the social work, help to interpret information to the donor, and attest to the willingness of the donor to donate.

However, these stipulations for a collateral person's involvement are ethically troubling. Firstly, while familism is a cultural norm in Singapore, we should not assume that all individuals share the same cultural values. Some donors may prefer not to have a family member participate as a collateral person or not to have a collateral person at all. Also, some donors may not feel close to their family and yet by HOTA's stipulation are forced to involve the family. For this group of donors, requiring a confirmation of the donor's decision by the family can be difficult when the family is likely not to understand well of the donor's values, preferences and life stated goals. It is unclear whether a collateral person is able to offer independent or objective views while respecting the views of donor. A collateral person may possess a different view on what it means to "act in the best interest of the donor." For example, if the collateral person's perspective is that avoiding physical and medical harm to the donor best serves the interest and well-being of the donor, then the collateral person may incline information and actions towards these aims, instead of respecting the donor's autonomy to donate. These practices incorrectly assume that the collateral person has a good understanding of the donor and has the donor's interest at heart or is in a better position than the donor to assess the appropriateness and readiness of the donor's intention; and that the risks to the donor's privacy presented by the collateral person's involvement are outweighed by the benefits of his/her inclusion.

Secondly, HOTA undermines donor autonomy in various ways. When the family member functioning as the collateral person is allowed to air his/her views to the evaluator, and despite HOTA's clause that any family's objection to the LKD should not *automatically* disqualify the donor but that the objection should be factored into the evaluation, there is a clear

indication that the collateral person wields some degree of influence in potentially preventing the donor's LKD. This undermines the donor's autonomy. HOTA diminishes respect for the donor's autonomy by another notch when the family's confirmation of the donor's willingness to donate is required. The proof to confirm the donor family's knowledge of the LKD decision implies that a voluntary and informed decision by the donor is still inadequate by HOTA's standard. If the rationale for this is prompted mainly by the societal and cultural value of familism and by a belief that keeping the family apprised will contribute to family cohesion, or at least to minimize disharmony corollary to an LKD that the family has no prior knowledge of and finds objectionable, perhaps it should suffice that the donor is encouraged to keep the family informed.

Moreover, to require proof of the family's knowledge of the LKD decision places unnecessary pressure or burden on the donor of an autonomous LKD decision. Also, the presence of a collateral person may in itself undermine the autonomy of the donor by invading his/her privacy and present the risk of breaching the donor's confidentiality. Again, this requirement offers no consideration to the those donors whose lack of familial closeness or whose preference is not for familial involvement will either have difficulty or reservation having their family involved in the LKD process.

Thirdly, by requiring that a collateral person reaffirm the donor's willingness to donate—as HOTA's way of seeking confirmation that the LKD is voluntary—the voluntariness of the donor could be compromised instead. When the donor has to attest to the collateral person that he is a willing donor, the donor will more likely feel the need to deliver his pledge for LKD such that any subsequent change of mind against donation might create greater difficulty for the donor who wishes to rescind his/her decision. The donor might feel compelled to live up to a witnessed promise to donate, and for those intra-familial donors, this pressure would likely be greater.

Further, the donor may not sincerely wish to donate even at the beginning, but be pressured to offer to do so with the presence of the collateral person ensuring that the donor follows through.

Fourthly, requiring a collateral person to reaffirm the donor's willingness to donate suggests that HOTA doubts a donor's capacity to decide independently. If a donor is incapable of independent decision, then, such a donor is not fit for LKD. Further, the need for the family to reaffirm the donor's willingness places undue burden on donor's family because they are now drawn into the donor's otherwise autonomous decision and has to find means for confirming the donor's willingness to donate and present their conclusion to the TEC.

Finally, the requirement for corroboration of the donor-recipient emotional bond by an independent third party or documentation suggests doubt in the veracity of donor information and assumes that the collateral person will not be coached to couch his/her information to align with the donor's version in a bid to present a favorable impression to the evaluator with the aim of meeting the criteria for donation candidacy.

Because the manner of involvement of the collateral person as indicated by HOTA presents ethical concerns, I offer alternatives here for his/her involvement that aim to protect donor autonomy and confidentiality and to safeguard the well-being of the donor. Ideally, the donor should have the right to decide whether a collateral person is to be included in the evaluation session, and if so, who that person would be. However, because of the HOTA's requirements, the donor needs to be advised of why producing a collateral person is a procedural necessity and that even if a collateral person is not involved in the psychosocial evaluation, it cannot be avoided from the TEC evaluation. In light of the right of the TEC to involve a collateral person, it would likely serve the donor better to have a collateral person involved in the psychosocial evaluation. Yet within such constraints, respect for donor autonomy can be

demonstrated by letting the donor decide on the collateral person's degree of involvement in the psychosocial evaluation. Instead of participating in a quasi-policing function with regard to what the donor states regarding the donation motivation during the psychosocial evaluation, I suggest that the collateral person should be regarded as the donor's resource or support person whose role is to uphold the interest of the donor as that interest is defined by the donor based on the donor's values and perspective. The collateral person should not be functioning as a corroborator to verify donor information.

Most importantly, I suggest that the collateral person should be involved in the interview only after the donor has been evaluated. Following the evaluation, the social worker should inquire whether there is someone that the donor would like to inform regarding his/her decision to donate a kidney. That is, the collateral person's involvement should not be part of the donor psychosocial evaluation, but in a separate segment. The collateral person's participation in the interview should be limited to, for example, a verification of the donor-recipient relationship as required by HOTA, the exploration of the collateral person's support and role as a caregiver to the donor (if he/she is functioning as one), and the exploration of the views of the donor's key family members or significant other regarding the LKD decision. For all of the reasons discussed above, the collateral person should not be present during the previous evaluation.

The donor psychosocial evaluation should not have as a goal the uncovering of lies or untruth, as the social worker has neither the resources nor the authority to investigate organ trading and lies. The burden of insisting for and evaluating corroborative evidence should be a function of the TEC, since such matters pertain to the regulation and ethical evaluation of the LKD, whereas the social worker's role is that of ascertaining the psychosocial fitness of the donor. However, because the TEC is empowered to investigate the veracity of donor's

information, the social worker can advise the donor of the need for veracity in the information provided during the psychosocial evaluation, since an evaluation report will be provided to the TEC and the TEC will inquire and investigate as they deem fit. If the donor is unsure of any pertinent information, the donor should find out or verify. A collateral person need not be present to supply the information; the donor can seek it. The evaluation should be based on mutual respect whereby the donor provides accurate information to the social worker, and the social worker believes in the authenticity of the donor's information, and that there should be respect for donor autonomy.

The social worker should also advise the donor that the TEC can bring in multiple collateral persons or have repeated interviews with collateral person(s) to reaffirm the donor's willingness to donate. However, the donor should not think that because the collateral person has confirmed the donor's willingness to donate, he/she must therefore carry out the LKD. It is important that the social worker affirms the donor's autonomous right to withdraw his/her decision to donate at any time.

While involving a collateral person appears to proffer psychosocial benefits [16, 17, 66] these advantages are assumed at best. No studies have been conducted that measure the impact of a collateral person on the donor psychosocial evaluation or LKD outcome. On the other hand, ethical infringements consequent to having a collateral person are more apparent than the supposed psychosocial benefits. Involvement of a collateral person should therefore be carried out with circumspection so that benefits from such an involvement, if any, will be optimized for the donor psychosocial evaluation without violating ethical principles. Transplant programs should remain flexible and consider on a case-by-case basis whether a donor should be encouraged to invite a collateral person to the donor psychosocial evaluation.

## **5.0 THE SOCIAL WORKER'S ROLE**

In Singapore, HOTA has stipulated the psychosocial evaluation as a role of the social worker. I will argue that social workers, or others with similar training, are indeed best suited for this role.

The professional preparation of a social worker equips him/her with the necessary knowledge, competencies and ethical training that enables him/her to execute the tasks of a donor psychosocial evaluation. The evaluation domains comprise a comprehensive assessment of an individual donor's psychosocial functioning and situates the donor in the context of his/her family and social relationships, obligations and resources. Because social workers are trained in theories related to the individual, family and society, they are well-positioned to assess the needs and functioning of individuals, groups and families and the interactions between these systems. In addition, they can appreciate how relationships can affect decision making. Similarly, the social worker is able to understand macro influences such as cultural and societal values and how they may shape individual decisions for related and unrelated LKD. Depending on the individual, family and societal expectations on role performance can either be positive motivators or coercive factors for LKD. The systems perspective guiding social work practice enables the social worker to assess the confluence of individual values and life goals, and family and societal elements in motivating LKD.

Social work education immerses the professional in a spectrum of theories ranging from individual to the society at large. For example, identity theory is a micro-sociological theory that attempts to explain how self-identities influence an individual's role behavior [67]. It has been

utilized in empirical studies to explain blood and organ donation behavior [68, 69]. Individuals occupy various social positions in their life that are accompanied with social roles. Each social role is a set of duties, expectations and behavior that they are expected to fulfill. Social expectations of role fulfillment can be formed by family, cultural community or the society, and a failure to conform to the expected role may result in disapproval by the reference group [67]. Intra-familial LKD, and in particular donations from parents, can be viewed as a fulfillment of a social role and set of expectations (e.g., to provide for the needs of offspring) that society may implicitly expect of an individual. A parent, in identifying with the social role, feels the need to protect his/her offspring from illness, disability and the throes of dialysis treatment by donating a kidney. However an individual may face undue pressure in living up to such a social role. Undue pressure in this context would be pressure that is more powerful and more stringently motivating than is typically exerted within or on families, or pressure that is more than usually controlling of the individual agent's decision. Studies examining LKD motivations have documented donors' decisions as attributable to their sense of role obligations [51]. Sheafor and Horejsi [70] describes "assessing a client's role performance" as among the social worker's functions. The social worker's theoretical foundation enables him/her to assess whether role fulfillment results in role conflict or ambiguity, as well as whether an individual is perceiving stronger than usual pressure—either from others or as a result of "internal pressures," such as exceptional emotions, psychological needs, or beliefs about others' expectations. By training, the social worker is sensitive to how family, relationships, cultural and societal influences affect LKD decisions. Because of social work emphasis on individualism, and through utilizing their repertoire of interviewing, exploring, questioning, clarifying and engaging skills, coupled with their professional value of providing an accepting, non-judgmental and supporting environment,

the social worker is able to explore the motivations and voluntariness of LKD decisions, and assess how familial and societal influences may exert undue pressure on the donor. The social worker must probe the individual donor's values and perspective in order to form a basis on which to judge whether the pressures to donate that the donor is experiencing are undue and ethically problematic, or whether they accord with the pressures and values that donor embraces.

Another reason why the social worker is best suited to perform the psychosocial evaluation of the donor relates to the social work core values and how they parallel the goals of the psychosocial evaluation. The core values of the social work profession are service, social justice, dignity and worth of the person, importance of human relationships, integrity and competence.

The social justice value guides the social worker to help ensure that all medically and psychosocially suitable candidates are able to donate a kidney without their doing so posing an unnecessary risk of burdening current or future social resources. Social justice demands that, in keeping with other social resource allocation decisions, LKDT not be limited only to the rich or socially powerful, and that the opportunity to be altruistic not be limited only to some socially privileged individuals. Ensuring fair access to the myriad potential benefits of LKDT must be balanced against the risk that a donor may become a social burden if she or he lacks sufficient personal financial resources and social support. Thus, the social worker should ensure that the LKD will not compromise the well-being of the donor through undertaking unreasonable risks. Social justice considerations also require that the social worker acts to prevent LKD that may endanger the recipient's safety, as when a donor's high risk sexual behavior places the recipient at risk for contracting sexually-transmitted infections. At the same time, social justice demands that the social worker not act prejudicially, but instead pursues the least restrictive intervention in

the autonomy of a willing donor, which in this case would require careful assessment of the actual risk the donor presents to the recipient's health through the organ to be transplanted, and not merely ruling out classes of individuals based on their characteristics or behaviors. The social justice value requires that the social worker seeks to protect the interests of the disadvantaged and vulnerable groups, which includes the poor, sexual minorities and those with histories of substance use or other high risk behaviors. In this regard, the social worker will ensure that donors from such population groups are recommended for LKD based on individual assessment of the risk-benefit ratio associated with their donation and that they, like all candidate donors, can be adequately connected to resources that will bolster their coping with the demands of an LKD, while at the same time seeking to ensure that they are not taken advantage of due to their vulnerable social status. In acting in alignment with the demands of social justice, the social worker will also empower donors by not supporting LKD decisions that are coerced or made under undue pressure, or where there are prohibited inducements. On the other hand—as an expression of respect for donor self-determination or autonomy—the social worker will support a donor's informed and voluntary LKD based on the donor's personal values and life goals. Doing so respects the inherent dignity and worth of the donor, another social work value.

Social work regards the individual as a social being, appreciating that individuals exist in relationship with the others in his/her environment. In virtue of its emphasis on the importance of human relationships, social work training helps to understand how kinship and emotional bonds motivate LKD decisions and why a person would be willing to undertake risks for the benefit of another. Such an awareness is integral to the psychosocial evaluation process. Further, although beyond the purview of the psychosocial evaluation process, intervention to optimize the positive effect or attenuate any negative impact—whether biological or emotional related ones—

that LKD may have on the donor's significant network may be arranged by the social work profession who has both skills and professional contacts pertinent to such intervention. Having established a relationship with the prospective donor during the evaluation process may facilitate post-donation intervention should it become necessary or desired by the donor.

Further, social work's professional value of integrity translates into maintaining client confidentiality, and this is important so that the donor can have the confidence to divulge personal and sensitive information to the social worker during the evaluation process. In adhering to the requirements of competence, the social worker is committed to possessing adequate and updated kidney transplant-related knowledge and skills to ensure proficient and professional services for the benefit of the donor-patient as well as the transplant program.

Clearly, the nature of the social work profession, social work education and social work values predispose the social worker as the professional well-suited for conducting the donor psychosocial evaluation. Other professionals may have similar knowledge, competencies, skills, and ethical commitments. These characteristics associated with social work should serve as a model for those qualities of preparation and professional activities requisite to conduct the psychosocial evaluation. It is the substance of social work training and practice—not the label “social worker”—that is most important for successful psychosocial evaluation of candidate donors. The title of “social worker” may itself have some particular benefits, as other professional titles may present some confusions or barriers to psychosocial evaluation. Some people are reluctant to consult with a psychiatrist or psychologist, believing that to do invites the stigma of mental illness or reflects an unacceptable vulnerability. The title of “social worker” may be more acceptable to these individuals, may make them feel more comfortable and may result in a more open exchange of information and discussion of feelings. For physicians to

conduct the psychosocial evaluation might confuse prospective donors by blurring the line between medical and psychosocial criteria for acceptable candidacy. Moreover, few physicians have the relevant training to elicit emotions and motives, to discuss psychosocial needs, to intervene in intra-familial or interpersonal conflicts and to connect patients to social resources to support their decision making and post-donation care. Finally, those trained in medical ethics or bioethics may not have the skills of psychosocial assessment or ability to connect patients to social resources that social workers do.

### **5.1 AVOIDING PERSONAL VALUES IN PSYCHOSOCIAL EVALUATION**

Social workers—while well-positioned to perform the psychosocial evaluation of the donor—must adhere to the criteria presented in the evaluation framework and avoid introducing or imposing their personal ethical values in the evaluation process. Doing otherwise may violate many of the social work values, such as respect for client autonomy, respect for the dignity and worth of the client, integrity and social justice. Imposing one’s own personal values also disempowers the donor, which is contrary to the objective of social work. Social workers are trained not to be judgmental—i.e., not to express moral judgments about their clients’ values or actions, and especially not to exhibit disapproval of clients’ values, lifestyles and choices. Instead, social workers seek to help clients make their own values and decisions effective in their lives, albeit within the social framework of legal norms. Thus, for example, a social worker’s concern about a candidate donor’s high risk sexual behaviors or substance use should be for the donor’s own health and the potential for health risk a donor organ may present to its recipient, but should not result from (or express itself in) moral disapprobation or concern for the moral fabric of society.

Organ donation decisions are affected by personal beliefs and attitudes, which in turn are influenced by cultural, religious and societal attitudes, beliefs and values [71]. The diversity of views and values must be respected. As a part of professionalism and in order to seek a requisite degree of objectivity, social workers should not allow their personal views and ethical values to influence their assessments of LKD requests. For instance, a social worker may feel that people should not undertake unnecessary risks, especially if doing so may compromise the well-being of those whom one is morally obligated to, such as dependent children. Based on this value, the social worker may not be in favor of a father with teenage children offering an unrelated LKD. Acting on this personal value, the social worker would therefore not recommend this man for unrelated LKD, but doing so would fail to evidence requisite respect for his personal values and autonomous decision making, and would unfairly exert inappropriate power over his access to the opportunity to be altruistic. His reason for donating a kidney could be that as a philanthropic millionaire, the practice of donating money lacks meaning because it does not involve a sense of sacrifice since he is giving away excess money for which he has no need. To feel that he has lived his life meaningfully, he finds it important to sacrifice something that will significantly benefit another person and decides that donating a kidney is what will help him achieve his life goal. The social worker, in allowing his/her personal values to interfere with the donor evaluation by not recommending this man for altruistic LKD is in effect obstructing the man's exercise of autonomy and achievement of life goals. These not only contradict the values and mission of the social work profession but also undermine the integrity of the transplant service and the ethical values in transplantation. Instead, his/her focus should be on ensuring that this man understands the reasons behind his decision to offer an unrelated kidney donation and that he has comprehension of the risks of undergoing a nephrectomy and the risks and potential

benefits of an unrelated LKD. If an unrelated LKD is indeed what he aspires to do, the social worker's role then is to support this man's informed and voluntary decision.

Because personal values may insidiously influence the type of assessments of reasoning and motives that are part of the psychosocial evaluation, the social worker must be mindful of his/her values and vigilant about not letting them interfere with the donor assessment. Having self-awareness of one's values is a cornerstone of social work practice. Transplant social workers should not only have awareness of their values pertaining to LKD and LDKT, but also actively evaluate their services to ensure that their personal values do not substitute the criteria stipulated in the evaluation framework. It may be helpful for social workers involved in these assessments to present their evaluations in case conferences to receive feedback from colleagues who may be able to detect patterns of bias or to discern the influence of personal values which the individual social worker him/herself cannot perceive. It may be helpful for the social worker to have an evaluation monitored periodically, just as clinical counseling sessions are monitored by a supervisor early in a psychologist's or social worker's training. Such periodic monitoring should not be punitive, nor be undertaken to insist that a social worker continually prove his/her competence and lack of bias, but instead should be conducted in a supportive manner to help social workers avoid bias or undue influence of personal values and prejudice, as well as to feel more confident in their ability to do so. Rather than such monitoring or case discussions resulting in a report on the social worker's professionalism and performance, such activities should be conducted in a supportive way to help social workers identify their individual biases and to provide them with resources to reduce their influence. In egregious cases, of course, unduly biased psychosocial evaluations should result in remedial training and, failing that, could result in the social worker being reassigned to other duties.

## 5.2 THE INFLUENCE OF CULTURAL AND SOCIETAL VALUES ON LKD

Added to the awareness of personal values and preventing these from influencing the donor evaluation, the social worker must also be cognizant of how cultural and societal values shape perspectives and decisions on LKD and LDKT. An awareness of such values will influence the social worker's empathy, competency, perspective and values when evaluating the donor's motivation and expectations regarding LKD. In light of Chinese familism, a Chinese donor would likely have higher acceptance for risk-taking in LKD and yet not necessarily perceive it as unduly burdensome, because he evaluates his decision in terms of how it benefits the family unit more than he would consider its impact on him as an individual. Chinese familism also implies that any lack of deliberation about LKD is only natural in Chinese families, leading to minimization of the importance of comprehension of LKD risks, potential benefits and treatment alternatives for the recipient. Cultural diversity, as well as diverse personal values, lead to variability in the interpretation of the acceptability of risks. In fact, endorsing an LKD that is made out of love or familism respects that individual's autonomy to live out his personal life and ethical values. Donating a kidney with an acceptable risk to self and thus acting in the interest of another person does not discount one's autonomy.

While it is important for the social worker to recognize the probably cultural dimensions of individual prospective donors' values, at the same time, however, it is important that due consideration is given to the values *actually subscribed to by an individual donor* and weigh these against the objective LKD criteria and risk data, rather than making assumptions about an individual's values based on his/her ethnicity, religion, or cultural traditions. While LKD decisions shaped by a sense of duty in familism should not be misunderstood as being unduly pressured, but appreciated as acts of familial commitment and devotion, social workers must be

careful to discern when undue familial pressure is masquerading as a cultural construct. Social workers must attempt to distinguish between felt pressures that are part of relationships—culturally influenced or not—through which an individual derives his sense of identity and fulfillment, and those pressures that the individual does not, in fact, welcome as part of his identity. A social worker possessing understanding of cultural influence on candidate donors will more effectively recognize and be able to evaluate the rationale and motivations behind the LKD.

Societal values also influence LKD policies and decisions. Germany only allows LKD among individuals who are biologically related or those who share an intimate emotional relationship. In Japan where there is low acceptance for deceased donor organ donation, LDKT is commonly pursued and constitutes about 80 percent of performed kidney transplants. Of these, slightly over a quarter are non-related cases [72]. In the USA, unrelated LKD is allowed, while it has only been permitted in Singapore since 2004. When a case emerged in 2008 regarding a Singapore retail tycoon charged in court for attempting a kidney purchase from an impoverished Indonesian man and making a false statutory declaration that he and his family were relatives, there was a heightened wariness locally regarding unrelated donors. Anecdotal accounts suggest public skepticism regarding unrelated donors' altruistic motivations and guardedness against financial incentives in non-related LKD. Since 2004 when unrelated LKDs became permitted, there have been only six unrelated LKD (S. Kong, June 6, 2015). HOTA was revised; clearer and stricter directives on living organ donations were disseminated to transplant centers and the TEC received more empowerment for its role. The chain of events reflected that legislative progress permitting unrelated LKD notwithstanding, the Singapore community appears vigilant toward it and such societal response potentially influence the donor psychosocial

evaluation. And in fact, HOTA indicates that LKD must consider “Singapore’s public interest and community values when assessing an application” [8], suggesting the need to incorporate societal values in assessing LKD requests. The prevailing societal norm regarding LKD suggests greater acceptance for related than unrelated LKD, and the former is reinforced by cultural value such as familism. However, societal norms or expectations can either be facilitative or coercive on an individual’s decision and their nature and degree of influence needs to be examined vis-à-vis the donor’s autonomous decision to donate a kidney.

An awareness of societal values allows the social worker to give due consideration to how these values shape the individual donor’s decision regarding LKD. Also the social worker has to be cognizant how these values may shape his/her personal view on LKD and prevent them from influencing the donor psychosocial evaluation. Failing to do so will be unfair to the donor and may fail to respect the donor’s autonomous decision making. For instance, in Singapore where there is still a lack of acceptance toward unrelated LKD, the social worker has to judiciously balance this with the donor’s autonomy to donate, but yet not allow it to determine the appropriateness of the donation. If it can be adequately established that there are no financial incentives in the LKD, and that the donor has realistic expectations and comprehension of the impact, and the risks and benefits of donating a kidney, then his autonomous decision should be upheld notwithstanding the prevailing societal caution regarding unrelated LKD. To fail to do so would fail to respect the donor’s autonomy.

If however, the candidate donor seeks to donate for personal gain, for example, to publicize the act in the media in hope of gaining increased social regard, the social worker may evaluate his motives with skepticism as to his suitability as a donor. This is not because his seeking positive publicity is contrary to the spirit of altruism that Singapore’s culture and law

have stated ought to be an attendant character of organ donation, as this rationale would substitute the social worker's values (or societal values) for those of the candidate donor—but instead the social worker may justifiably judge that the donor's expectation of positive media attention is not likely to be fulfilled in the Singapore context. Unmet expectation may be psychologically detrimental and increases the potential harm of LKD. While it must be recognized that the publicity seeker might simply lie and aver that his motives are altruistic; however, once the social worker is aware that he/she has these unrealistic expectations of personal gain, it would be wrong not to signal that his/her particular reasons for donation give him/her a less favorable risk to benefit ratio because of the likelihood that what he/she considers the benefit will not be realized.

The social worker is well-suited for performing the psychosocial evaluation of the living kidney donor, which should involve both psychosocial and ethical considerations. The utilization of an ethical framework for psychosocial evaluation of the donor in the absence of a universal, quantifiable psychosocial assessment tool allows considerations for particular contextual features of each case and the examination of risk to benefit ratio from the individual donor's perspective. Psychosocial evaluation, along with medical evaluation of the living kidney donor, functions as safeguard by preventing donations where the risks are significant or disproportionate to the benefit, or if the donor's comprehension of LKD is significantly inadequate. Therefore, in spite of the ethical challenges, justified decisions of LKDs are ethically sound and supporting an autonomous and informed LKD decision demonstrates respect for the individual donor's stated life values and direction.

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