Chapter 14
Contraindications to Living Donation from an ILDA Perspective

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The independent living donor advocate (ILDA) participates to help ensure that all living donors are fully informed, willing, and uncoerced volunteers, building from the important components of assessment and interaction as described by Sites et al.—independence, transparency, partnership, and advocacy [24]. The role of an independent advocate is essential because of the unique context of, and potential pressures associated with, living organ donation internal for the prospective donor himself/herself, from the prospective donor's loved ones, and from the medical team. As an independent clinician, unbiased by either connection to the intended recipient or having a stake in whether or not the surgery occurs, the ILDA is tasked with the overall review of potential living donors' understanding of process, risks, and rights. As such, the ILDA acts as a safeguard and assures and reinforces that elements of informed consent are met. Fundamentally, then, living donation is contraindicated from an ILDA perspective when the prospective donor does not meet the standards of informed consent [1, 21] (Table 14.1).

This chapter will provide an overview of ILDA-identified contraindications to living organ donation, utilizing key concepts of informed consent categorized broadly as lack of intentionality (or desire to proceed), lack of understanding of risks/benefits, and lack of voluntary status (presence of coercion) [8]. Although all health care workers participating in the evaluation process agree that living donors should be ready and informed volunteers, the assessment of elements of understanding and preparedness can be challenging in practice. This chapter will explore these factors, will offer practice strategies for assessment, and will describe unique aspects of the ILDA role in doing so. Using both literature and case examples to explore differences between areas of relative risk and outright contraindication, the chapter will offer guidance for clinical practice. Finally, it will describe strategies for communicating contraindication findings to the prospective donor and transplant team.

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J. Steel (ed.), *Living Donor Advocacy,* DOI 10.1007/978-1-4614-9143-9_14,

Table 14.1 Contraindications to living donation from an ILDA perspective

1.	Prospective donor does not want to proceed
2.	Prospective donor lacks adequate understanding of risks associated with donation or the donation process
3.	Prospective donor is not a willing and an uncoerced volunteer
	(a) There is evidence of secondary gain
	(b) There is evidence of coercive pressure

Background on ILDA Role and Practice

Before outlining specifics of these ILDA-identified contraindications, let us start with a brief overview of the ILDA role and purpose and a clarification of what the ILDA is empowered (and, conversely, not empowered or perhaps even qualified) to do. The ILDA serves as an unbiased resource for the prospective donor to learn more about the process and options; explores the prospective donor's understanding of surgical, medical, psychosocial, and financial risks; affirms understanding of process as well as follow-up recommendations; and confirms desire to proceed or assists with walking away (with the protection of confidentiality for the reasons why she/he does not want to proceed with surgery). Ideally, the ILDA supports and advocates so that all living donors are competent, fully informed, willing, and uncoerced.

To be clear: first, the ILDA role does not interpret medical or psychosocial risk profiles to make candidacy determinations (though if she/he serves in a dual role at the transplant center, these separate recommendations may be appropriate and necessary in the other capacity). Second, the ILDA does not trump prospective living donor autonomy to declare what is in his/her "best" interest (as in theory it would be in every person's "best" interest to avoid unnecessary surgery). It is not the ILDA, but rather the treating clinician (i.e., living donor surgeon), who formally completes the informed consent prior to surgery.

Individual transplant centers across the United States have operationalized the ILDA role in vastly different ways [25]. Other chapters of this book will explore recommendations for ILDA training, practice, and role throughout the living donation process. Certainly, during the evaluation process, the ILDA can participate in many ways to assist prospective donors throughout the process: via assessment, evaluation, psychoeducation, collaboration with transplant team members, and advocacy, all as central elements of practice.

In the varied and various ways that the ILDA role has been implemented, the ILDA must partner with potential donors to promote rights and understanding as part of the prospective donor's decision-making process. In so doing, ILDA also identifies barriers to prospective donors' provision of informed consent [15, 30, 31]. For example, the prospective living donor may not be able to understand or accept risks associated with donation. Essential to the ILDA role, then, is to be empowered to stop the donation process if elements of informed consent have not been met.

Of course, living donor candidacy criteria are defined by individual transplant centers. Previous research has shown broad differences in donor candidacy

requirements and processes in the United States [5, 20, 25]. Provided the donor evaluation process is consistent with the Center for Medicare and Medicaid Services (CMS) and the United Network for Organ Sharing (UNOS)/Organ Procurement and Transplantation Network (OPTN) guidelines (and there has been a move within regulatory agencies and transplant professional organizations to increase degree of standardization in this process), individual candidacy decisions and criteria are determined by the transplant facility. Regardless of how contraindications are specifically defined, ILDA review of prospective donor readiness and understanding—including identified contraindications—becomes part of donor candidacy discussion, and should be addressed within teams and at donor selection meetings.

Informed Consent

Informed consent for live kidney donation is a prerequisite—essential for living donor transplantation from ethical, legal, and regulatory perspectives. In general, informed consent occurs when a competent person makes an autonomous choice about whether to access medical treatment, armed with adequate information and understanding regarding risks, benefits, and expected outcomes [2]. The patient's intention to proceed, understanding of process and benefits, and free will to decide are fundamental. However, as Valapour noted, these factors may be present along a continuum of clarity/confusion [32]. Informed consent can also be described as a reciprocal process between clinician and patient of information disclosure, processing, and decision making. Much has been written describing the challenges associated with determining adequacy of informed consent for living organ donation, a procedure lacking medical benefits for the participant and therefore demanding a high standard of careful process and communication. Living donor transplant has the added challenge of being a shared transaction, in which the living donor's informed consent must also include understanding of the intended benefits, options, and expected outcomes for another (the recipient) [4].

In "Informed consent in living donation: a review of key empirical studies, ethical challenges and future research," Gordon summarizes goals of the process as follows:

> The principle of respect for persons requires that potential LDs be competent and informed, and comprehend the risks to themselves of undergoing the procedure, as well as the risks, benefits and alternatives available to the recipient. The consensus conference on Living Kidney Donor Follow-Up emphasized the critical need to inform donors about risks specific to themselves. Further, potential LDs must be willing to donate and be free from undue pressure to consent to the procedure. Moreover, respect for autonomy means that LDs have the right to determine how much risk they are willing to accept, and conversely, that LDs (and the recipients) have the right to refuse the donation. [9]

In practice, though, living donor informed consent processes have been shown to vary widely across transplant programs in the United States and worldwide, with wild discrepancies noted in standards, consistency, and practice [9, 16, 32, 33]. In

separate pieces, both Gordon and Rodrigue et al. identified significant "variability and deficiencies" in the consent process across the spectrum of living donor care [9, 20]. While many of the studies reviewed care prior to implementation of newer living donor safeguards (including OPTN Living Donor Informed Consent Guidelines; provision of follow-up care for living donors for 2 years; and implementation of the ILDA itself), concerns raised about variability in the quality of informed consent process continue to be valid. Regulatory and professional organizations have called for strengthened processes, and for standardized elements of disclosure and education, including separating the consent process for living donor evaluation from consent to proceed with donation (Table 14.2) [9, 15, 16, 27, 30–33].

Table 14.2 Guidance sources

Guidance sources	These references can be found at the American Society for Transplantation website, in the Living Donor Community of Practice section
CMS	Conditions of participation and organ transplant interpretive guidelines 2008 (pp. 77–85)
UNOS	Policies 12.4 (independent donor advocate (IDA)) 12.4.1 (IDA role) 12.4.2 (IDA responsibilities) 12.4.3 (IDA protocols)
OPTN	Guidelines for living donor informed consent http://optn.transplant.hrsa.gov/ContentDocuments/Living_Donor_Kidney_Psychosocial_Eval_Checklist.doc http://optn.transplant.hrsa.gov/ContentDocuments/Living_Donor_Kidney_Medical_Eval_Checklist.doc http://optn.transplant.hrsa.gov/ContentDocuments/Living_Donor_Kidney_Informed_Consent_Checklist.doc

CMS Center for Medicare and Medicaid Services, *UNOS* United Network for Organ Sharing, *OPTN* Organ Procurement and Transplantation Network

Elements of Informed Consent

Willing Volunteer

On its face, lacking desire to proceed is a straightforward contraindication to living organ donation. The living donor must be a willing volunteer. Valapour framed this component of informed consent as "intentionality," and defined it as an "absolute condition, that is, an act that is either intentional or not" (Table 14.3) [32]. Of course, at any time during the living donor evaluation process, the potential living donor has the right to stop the process. The ILDA (or, one would hope, anyone on the transplant team) would identify this as a contraindication, and assist the potential donor with walking away, while de-

Table 14.3 Basic components of informed consent

1.	Intentionality
2.	Understanding
3.	Noncontrol (language beautifully outlined by Valapour [32])

signing a strategy amenable to the potential donor that preserves relations with the intended recipient.

However, sustained ambivalence and experience of "pressure" (internal and external) around organ donation decision making is not uncommon [7, 14, 33]. Importantly, the literature suggests that donors who describe ambivalence at the time of donation are at higher risk for poor psychosocial outcome [7, 26]. Transplant programs have integrated various strategies to assist prospective donors struggling with ambivalence, including a "cooling off period" [20], a "scaling system" of desire and readiness, referral to psychosocial providers for counseling/support, and, most recently by Dew et al., interventions utilizing motivational interviewing approaches [7].

The ILDA is ideally positioned to check in with the potential donor about the status of "intentionality" and stage of decision making at several steps in the donor evaluation process. The ILDA may meet with the potential donor early on to learn about motivation and conduct review assessment after the potential donor completes medical testing. The ILDA may also serve as the prospective donor's "voice" at donor candidate selection meeting: to forward lingering questions to members of the transplant team for discussion and input and also to articulate the prospective donor's desire to proceed (or not).

The profoundly ambivalent potential donor, who has not decided to proceed but has also not decided to close out the donation process, also benefits from specific aspects of the ILDA role and advocacy. Ultimately, a decision to proceed (or "intentionality") is necessary to be a living donor candidate. Given that informed consent is an affirmative action, for the purposes of living donor candidacy, "not deciding" must be the same as "deciding not to" proceed. As such, the ILDA can advocate for "cooling off" periods, and ways to ensure that the potential donor has had reflection time.

The ILDA also helps the prospective donor identify ways to resolve ambivalence. In some cases, the ILDA assists the ambivalent donor in accessing additional information about medical and psychosocial candidacy to aid his/her decision making. The ILDA advocates for this feedback, with the caveat that candidacy decisions have not yet been made. From an ILDA perspective, living donation is contraindicated until the prospective donor decides he/she wants to proceed. Holding to this standard during donor-candidate selection meeting helps preserve the "medical out" option.

Suggestion of Coercion

Prospective living donors do not decide to proceed in a vacuum. By definition, living donation decision making occurs with the hope of helping another. It is a shared transaction. Not surprisingly, then, studies have shown that contemplation about living donation is affected by feelings of pressure and obligation, both internally felt and externally imposed. These feelings may be positively expressed through role identification and aspirational identity: "this is what families do for each other" or "this is what [my faith] leads me to do." They may be felt internally as a weight associated with knowledge about benefits of living donor transplant for the recipient; pain seeing a loved one suffer; or desire to "save" another loved one from pressures to donate (most commonly in my clinical practice young adult children) [28].

Although these emotions can be experienced as difficult to weigh and sort, it is rather elements of external, coercive pressure that threaten potential donors' autonomous decision making. In a survey of 262 living donors, Valapour et al. found that 40% described feeling some level of pressure around donation [33]. "Influences affecting the voluntary nature" of informed consent ran along a continuum, with the mildest being persuasion, midline being manipulation, and most severe being coercion. Not surprisingly, data showed that living donors experiencing the highest degree of (presumably, external) pressure around decision making also had the highest rate of "unsureness" about whether they would choose to donate again [3, 7, 33].

Although a psychosocial evaluation during workup will certainly explore the prospective living donor's motivations and risk of experiencing pressure to donate, the ILDA evaluation serves as a secondary check to ascertain whether a potential living donor is free to choose to donate (or not) without inducement or fear of reprisal. Interviews elicit distinctions between internalized pressure often associated with living donor decision making and external pressure affecting potential living donor autonomy and safety.

When coercive pressure has been disclosed, the ILDA (and other transplant team members) must provide the prospective living donor education about necessary elements of informed consent and discuss ways to stop the donor process. In these situations, careful strategy and rehearsal about next steps is often helpful (see Case Example 1). It is also conceivable for a potential living donor to disclose others' efforts to induce him/her to donate, and being able to make an autonomous decision to donate (or not) despite this pressure. In other words, it is the prospective donor's perception of this pressure, and its influence on decision making, that is important in determining whether autonomous decisions are possible. If autonomous decisions are not possible, here, too, the ILDA assists with various options for walking away, including use of a "medical out."

Case Example 1: Presence of Coercion

Details have been changed to protect patient confidentiality. The ILDA is a member of the Patient Relations Department at the hospital; nurse by training.

A 23-year-old man presents for donor evaluation; his sister is on the transplant wait-list for a third transplant. All team members note anxiety and pressured responses. His mother (recipient's mother too) contacts the transplant center repeatedly to request updates on his workup; she is advised of Health Insurance Portability and Accountability Act (HIPPA) restrictions. He believes donation is the "right" thing to do, and resents that it is "expected." He does not want to donate, but is not sure if he could live with himself if he does not. During ILDA phone assessment, he describes being "blackballed" until he proceeds with donation. ILDA labels this behavior as coercive, explains this is unacceptable, and suggests that the patient meet with the donor team members to strategize next steps. Donor evaluation process is stopped and medical out is provided, with rehearsal by both donor social worker and transplant coordinator.

Direct Payment

As outlined in the UNOS Guidelines for Living Donor Care, donor consent must include disclosure that "it is a federal crime for any person to knowingly acquire, obtain, or otherwise transfer any human organ for valuable consideration (i.e., for anything of value such as cash, property, vacations) . . ." [15]. As part of review of informed consent, then, ILDA assesses whether prospective donors understand these provisions, and in turn whether they agree to abide by them. Secondary gain as a factor in living donor motivation or decision making is a contraindication to candidacy.

The National Organ Transplant Act of 1984 (amended in 1988 and 1990, and colloquially known as NOTA) outlawed the sale of human organs [18]. Since then, as the organ shortage has grown, organ trafficking and international "transplant tourism" have been major ethical concerns for the United States and worldwide transplant community [14, 17].

Concerns about unregulated organ sales and transplant tourism continue to mandate careful evaluation and assessment of prospective donor's expectations, especially as more potential donors present to transplant centers without an emotional connection to their recipients (and so, presumably, less likely to observe the kidney transplant recipient benefiting from living donor transplantation). The number of first-degree relatives as living donors continues to decline [5]. Although in 1989, only 8% of transplant programs would consider a nondirected donor, by 2007, 61% of responding programs evaluated nondirected donors [20]. Recommendations from a UNOS, AST (American Society of Transplantation), and ASTS

(American Society of Transplant Surgeons)-sponsored consensus conference on the care of the living unrelated kidney donor recommended that evaluation processes and structure be fundamentally the same, regardless of the relationship (or lack thereof) between donor and recipient [6]. In all cases, including those lacking prior relationship, shared understanding of expectations and degree of (or limits to) future relationship between donor and recipient (including lack of financial relationship) be agreed upon prior to proceeding. During prospective living donor evaluation, the psychosocial assessment explores risk factors for secondary gain as a driving force behind prospective donor motivation. These in turn are linked to problems of pressure and/or coercion. Members of the transplant team should provide psychoeducation about NOTA provisions, and seek prospective donor response to the same, clarifying guidelines and options for next steps, including ways to walk away from donation process. If psychosocial assessment identifies areas of risk, including concerns about prospective donor transparency, the donor social worker may conduct further assessment, seeking consistency in descriptions of motivation, sustained interest and coping with a prescribed "cooling off" period, or consistency between desire to donate and other behavior (such as volunteer work, etc.). Recommendations regarding risk factors will be contained within psychosocial assessment and reviewed during donor candidacy meeting.

It is the ILDA role, then, to review prospective donor understanding of the guidelines, agreement to abide by them, and confirm prospective donor's desire to proceed with donation given these parameters. If any of these conditions are not met, ILDA presents this finding at donor selection as a clear contraindication to donor candidacy. For example, in rare cases, a prospective donor may disclose offers of secondary gain as coercive pressure or that he/she was unaware of NOTA provisions prior to presenting for donor evaluation (see Case Examples 2 and 3). As an independent and transparent advocate for donor rights and understanding, ILDA is uniquely situated to help these prospective donors and the transplant team craft a graceful way out that minimizes risk of negative impact, given that coercive pressure may be in play.

However, ILDA can also assist the prospective donor—and the transplant team—in sorting through considerations about secondary gain that can be confusing in practice. To summarize a few historic examples, a previous controversy about whether paired kidney donation constituted secondary gain was clarified only with the passage of the Charlie W Norwood Living Organ Donation Act in 2007 (Public Law 110–144), finding paired kidney donation acceptable under NOTA [18]. Similarly, it has been generally agreed that donors can be reimbursed incidental costs of organ donation, including travel and lost wages. Therefore, while it is clearly illegal to profit from donating an organ, getting reimbursed for expenses is acceptable. It is common for ILDA to help prospective donors clarify understanding of these general guidelines.

However, in other cases, what constitutes "valuable consideration" can be confusing. ILDA discussion with prospective living donors can identify areas of question. When in doubt, ILDA can help prospective donors access clarification,

including hospital ethics consult. Following are a few examples from my own practice, without clear answers: if a prospective living donor gets a long-term increase in health insurance premium costs, presumably related to the impact of living donation, can the recipient cover these new costs? If a living donor delays accepting a new job in order to donate, can he/she be reimbursed potential lost wages? (see Case Example 4). In each of these examples, the prospective donor declared himself/herself unable to proceed without the assistance and wanted to comply with the law.

Defining the role of the ILDA here helps determine practice and next steps. After all, few, if any, ILDAs are attorneys expert in NOTA law; although all ILDAs should be well-versed in general concepts of medical ethics, not all ILDAs will be seasoned members of a hospital ethics committee. Therefore, in assessing secondary gain as a contraindication to donation, it is *not* the ILDA role to interpret NOTA per se. Rather, ILDA reviews prospective donor understanding of provisions and consent to abide by them, and partners with the prospective donor (and the transplant team) to clarify areas in question.

Case Example 2: Secondary Gain

Details have been changed to protect patient confidentiality. In this case, donor social worker is also an ILDA.

A 31-year-old woman presents for donor evaluation, hoping to donate to a distant cousin. She learned of the recipient's health status via a social media posting, and has been emailing directly with the recipient since then. During psychosocial evaluation, the prospective donor states calmly that the recipient told her insurance would pay a $ 20,000 fee for donation. As a result, finances are not a worry for her during her time off work. Donor social worker/ILDA clarifies that in the United States, no insurance will pay cash for a kidney, and in fact, this is illegal. Informed consent documents are shared to shed further light on the regulations. The prospective donor is dismayed. She feels "duped" by the recipient, and wishes to withdraw from donation. She states that the payment is not what drew her to donate, but that the false offer of cash leaves a "bad taste," and she will not trust future communications with the intended recipient. However, she does not want to confront the recipient, as she is afraid of family "backlash" for withdrawing.

ILDA collaborates with her and with the rest of the transplant team to end the donor evaluation. The clinician helps the prospective donor rehearse what to say within her family (though this rehearsal might not have been conducted by the ILDA had the ILDA not been a clinical social worker). The prospective donor is found to be "not a candidate" at donor selection, a finding which is transmitted back to her and (at her request) to the intended recipient.

Case Example 3: Secondary Gain

Details have been changed to protect patient confidentiality. In this case, the ILDA is a nurse coordinator who works as part of an independent living donor team (ILDT).

A 46-year-old man presents for donor evaluation, with intended recipient his brother. Intended recipient also owns the duplex in which they both live. Prospective donor is guarded, speaking in monosyllables when possible, and although each member of the ILDT gets the "feeling" that he is unenthusiastic, no one is able to engage him around these questions. Finally, during a follow-up phone call to share findings of the donor evaluation, prospective donor discloses that he has been advised that donating a kidney is the way he can avoid being evicted. He reports he "does not really have a choice." ILDA/coordinator is able to review concepts of secondary gain with him, and encourages him to reconnect with donor social worker for further discussion and intervention. Donor social worker helps prospective donor define elements of coercion and distinguish these from desired family roles and connections. In turn, donor social worker and ILDA/coordinator work together with prospective donor to identify ways to walk away from donation process. Prospective donor is found to be "not a candidate" at donor selection.

Case Example 4: Secondary Gain

Details have been changed to protect patient confidentiality. In this case, the ILDA is a chaplain who meets with donors at the end of the donor evaluation process.

A 22-year-old man accompanies his father to his transplant evaluation, expresses an interest in living donation at that time, and is advised that once his father is declared a transplant candidate, he can be scheduled for donor workup. Intended recipient's case is complex, and it takes months to meet candidacy criteria. In the meantime, the prospective donor is charged with minor crimes and sentenced to several months of jail time. Upon his release, he completes in-person donor evaluation. Briefly, his donor workup is WNL (within normal limits); he meets medical and psychosocial criteria, although he is noted to have a moderately high psychosocial risk profile. In reviewing informed consent documents with the ILDA, prospective donor notes that he was advised at a court hearing that "if I donated a kidney, the judge would take this under advisement" regarding sentencing for other, still-pending charges. Although prospective donor advised ILDA that this was not a factor in donation decision making (and ILDA found this to be believable, given prospective

donor's longstanding interest in donation and status as caregiver for intended recipient), both the prospective donor and ILDA wondered whether this statement constituted "valuable consideration" in the context of living donation. ILDA assisted prospective donor in seeking input from the rest of the transplant team and, ultimately, the hospital ethics committee. Ultimately, prospective donor proceeded to donation, but did so after completing legal obligations.

Understanding Risks

As is outlined in UNOS policies for living donor care, the ILDA reviews prospective living donor understanding of the donor evaluation process; the medical, surgical, and psychosocial risks of living donation; and the understanding of treatment options and outcomes for the recipient [4, 15, 19, 31]. This has been identified as a key element in the care of living donors, and is of particular interest given the literature suggesting that past living donors lacked knowledge and understanding prior to proceeding [9, 20, 33]. As such, from an ILDA perspective, living donation is contraindicated if the prospective living donor does not understand the risks associated with evaluation and donation.

If lack of understanding is identified as a barrier to candidacy, ILDA should share specific concerns with transplant team members, advocate for prospective donor to receive additional assessment, education, or intervention as indicated, and conduct follow-up assessment. In general, lack of understanding may be attributed to cognitive deficits that preclude provision of informed consent, inadequate integration or understanding of risks/benefits as described by transplant team members, or evidence of significantly unrealistic expectations associated with donation. If, after follow-up assessment, the prospective living donor still cannot reflect back understanding of risks, expected outcomes, or significant aspects of the process, then elements of informed consent have not been met, and ILDA should summarize these concerns at donor selection meeting and recommend against proceeding.

Certainly, in the role of an independent, unbiased partner through the process, the ILDA is uniquely situated to help prospective donors assemble, and assess, global understanding of risks as described throughout the donor evaluation process and by many team members. ILDA checks in with the prospective donor about takeaways from education provided variously, and at many time points, by nurse coordinator, physician, and social worker. ILDA assesses whether the prospective donor has processed, and retained, fundamental points acquired throughout, including understanding of medical, surgical, and psychosocial risks of proceeding; need for follow-up care; expected outcomes for donor and recipient; and treatment options for the recipient. Assessment at this stage further allows prospective donor to integrate both globally understood risks of living donation and risks/impact specific to the potential donor's health history and risk profile (see Case Examples 5 and 6).

Case Example 5: Patient Understanding

Details have been changed to protect patient confidentiality. In this case, the ILDA is a social worker. Donor psychosocial assessment was conducted by health psychology.

A 27-year-old single man hopes to donate a kidney to his mother, presents as strongly motivated to proceed, and says he would be willing to undergo "any" risk to help his mom. He lives with his parents and works part-time. Health psychologist identifies some cognitive impairment, learns he was in special education in school—diagnosis unknown to patient or family—and has never lived independently. Medically, his workup is WNL (within normal limits)—nephrologist and surgeon note patient participation in interview, whether his answers were short. ILDA notes that the patient is unable to read the consent forms and has some difficulty processing information provided.
At donor selection, ILDA voices concerns about patient understanding, at which time, team recommends additional evaluation. Neuropsychology finds prospective donor limited but competent, recommends oral teaching and repetition. Prospective donor, accompanied by his father (who was previously ruled out as a donor), eagerly participates in additional teaching sessions (with coordinator) by phone. Prospective donor phones in to ethics consult, voices his desire to donate and ably answers questions about risk. He proceeds to donate and reflects back positively on the experience.

Case Example 6: Patient Understanding

Details have been changed to protect patient confidentiality. In this case, the ILDA is also a social worker.

A 57-year-old woman presents as a potential nondirected donor. Medical and surgical evaluation identified many complex risk factors; psychosocial evaluation is WNL (within normal limits). Discussion at donor selection centered around prospective donor as high risk medically, but team determined she was a candidate if she understood her risk factors. In the interview with ILDA after medical workup was complete, prospective donor stated repeatedly that she would donate "if you can guarantee I'll be OK." She was not able to reflect back teaching provided by nephrologist, and instead stated, "I've heard donors do great afterwards." Despite repeated efforts at teaching and engaging by multiple team members, she was not able to reflect understanding of risks associated with donation, nor of her specific risk factors. ILDA documented her lack of understanding of risks, and of the informed consent process generally, as a contraindication to donation.

The ILDA participation at this stage is also an opportunity to help the prospective donor voice confusion and ask questions. ILDA can forward concerns to other team members for follow-up. In these cases, lack of understanding may not be a permanent contraindication to living donation, but may instead trigger additional (or adapted) teaching, or evaluation. ILDA forwards concerns about prospective donor's lack of understanding to other team members, who can then arrange additional consults—for example, neurology or psychiatry, and/or tailored teaching to accommodate learning barriers identified during psychosocial assessment (most commonly at our center literacy limits) [10]. ILDA can also assist prospective donor in asking specific questions of a transplant team member.

It is also not uncommon for prospective donors to voice that risks are of "no concern," and that they want to donate "no matter what." Many prospective donors share that the "worst news" would be a medical rule-out during evaluation. Simmons et al., in research dating back to the 1970s and 1980s, found that living donor (LD) decision making centers on moral, rather than deliberative, reasoning [23]. It is sometimes a clinical and practice challenge, in these cases, to help prospective donors slow down enough to process information about risk. As such, part of the informed consent process is to assess whether donors are able to process information and whether they have actually integrated it.

Structured interview with the ILDA helps potential donors focus and reflect understanding back. The ILDA can further promote engagement by encouraging the potential donor to invite a family member (often more concerned than the potential donor himself/herself) to participate in this learning and teaching, or the ILDA can otherwise strategize creatively. Formal evaluation, with the goal of reviewing what has been learned and what will be involved in consenting to donate, promotes potential donor participation. In this context, it is rare for a prospective donor to decline to participate.

That said, psychosocial status risk profile certainly affects patients' ability to integrate understanding of risks. Some people may lack the maturity to identify themselves as ever vulnerable to risk; others may demonstrate "magical thinking" about what living donation will do for the intended recipient. Each of these factors could be described as a relative contraindication or risk factor, warranting careful psychosocial assessment and review, and the ILDA role in this will vary according to the ILDA's professional background and structure of the role on the team.

Documentation of Findings and Next Steps

Guidelines for ILDA practice outline documentation requirements and have been specific about content areas [15, 29, 31]. If ILDA identifies a contraindication to living donor candidacy during assessment, this finding should be summarized and should appear in recommendations. Rationale and evidence should be available for review by transplant team members and by the prospective donor upon request. In turn, ILDA should participate in donor candidate selection meeting to discuss findings and assist in care planning.

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