7. Deciding about Living Organ Donation

Balancing Risk Management and Autonomy

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1. Introduction

The maxim *primum non nocere* – first do no harm – is beloved by medical practitioners. It is also valued by the public, who must place their vulnerable bodies in the hands of physicians and surgeons, trusting that doing so will leave them at least no worse off, and hopefully, somewhat better. Nevertheless, it is the more nuanced interpretation of the principle of nonmaleficence that has guided medical practice. This principle adjures practitioners to avoid and prevent harm to patients, and to ensure that if some risk of harm related to a medical intervention is inevitable it will be proportionate to the expected benefits of the intervention. The use of potentially harmful medical therapies and procedures has historically been justified by the claim that unavoidable risks are necessary, in order to restore or enhance the health of a person who would likely be worse off in the absence of the intervention. Thus, more practical advice was offered, allegedly, by Hippocrates to physicians, "'As to diseases, make a habit of two things – to help and not to harm.'" (Jonsen 2000: 2)

The principle of nonmaleficence accordingly entails a degree of caution, while permitting the experimentation and trial of innovations that have underpinned centuries of medical progress in the care of unwell or injured individuals. In 1954, this foundational norm of medical ethics was rocked by the first successful living donor kidney transplant (LDKT). (Mueller and Luyckx 2012: 1462) While the procedure posed risks for the transplant recipient, who otherwise faced an untimely death, it was the intervention in the living donor (LD) that established a paradigm shift in medical ethics: a fit young man underwent major surgery to remove a healthy organ for the purpose of improving his brother's health. Since that time, ongoing developments in living organ donation (henceforth "living donation") and transplantation have repeatedly challenged the established norms and frameworks of clinical ethics.

Ten years after the first successful LDKT, living kidney donation was still an infrequent and somewhat experimental procedure. At this time, Woodruff described necessary, but not perhaps sufficient, conditions for "volunteer kidney donation" (1964: 1458) to be ethically permissible. In essence he argued that the donation must be necessary; the intended transplant recipient must lack alternative treatment for their "gross and irreversible renal failure" (ibid.), that the donor must be healthy, such that they face little risk of harm from nephrectomy, and that the decision to donate must be voluntary and informed. Further, there must be reasonable certainty regarding the likely outcomes of individual procedures, in particular the probability of successful transplantation; "there must be no grounds for thinking that the chances of success are exceptionally poor in the case under discussion" (ibid.). These conditions reflect the ethical considerations that continue to guide living donation decision-making today, however the landscape in which they are applied has changed dramatically.

In this chapter, I explore a range of longstanding and emerging ethical considerations in directed living organ donation in the context of emerging clinical and scientific knowledge, changing clinical practices, and evolving norms.[1] I focus on the most common types of living donation, kidney and partial liver donation.[2] First, I consider the gradual change in attitudes towards the quality and proportionality of risks and benefits associated with living donation. I discuss the influence of emerging evidence and knowledge gaps relating to risks and benefits, and of the nature of prospective donor and recipient relationships on perceived ethical acceptability of donation. Second, I discuss ethical concerns about consent for donation with regards to decision-making capacity and voluntariness of prospective LDs. Third, I explore the issue of paternalism in donation decision-making, and tensions that arise between contemporary norms regarding respect for patient autonomy and the physician duty of non-maleficence. In conclusion, I suggest that instead of considering the ethics of LDT as inherently challenging the norms of clinical ethics, we ought instead to consider what we have learned from the ethically complex relational context of LDTs, and how this understanding might be applied in the wider field of health care decision-making.

2. Rethinking the Risks and Benefits of Living Donation

Overriding physicians' aversion to harming the healthy by surgically removing an organ was likely made possible by the fact there is an even more compelling professional intuition, namely that every effort must be made to save lives. When the likely benefits of donation include the sole opportunity to save the life of the intended transplant recipient, this heavily weights the scales of proportionality in favor of donation. For example, the imperative to save a life remains influential in the context of donations that may pose significant risks to donor health, such as liver donation which has

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[1] Broader ethical concerns regarding LD transplantation such as inequities in access to living donation and living donor transplants (LDTs), and inequities in the distribution of burdens of donation are explored only briefly in this Chapter. Factors that may influence decision-making about living donation are discussed primarily from the more individualistic perspective of clinical ethics. For example, financial status and gender of potential donors may contribute to systemic inequities in donation and transplantation and also represent important systemic socioeconomic inequities that are beyond the scope of this chapter. Instead such factors are considered with regards to their potential impact on the risks of donation. For instance, poverty may pose an additional risk to donor wellbeing if donation-related expenses are not covered. With regard to autonomy of donation decision-making, , a gender bias within some cultures may exert a coercive influence on female potential donors.

[2] Living lung lobe donation is also possible, however this is uncommon except in Japan (Date 2017). Living donation of intestines and pancreas is also possible but rarely occurs (Barr et al. 2005). Living uterus donation will be explored in the context of Chapter 15 of this book.

a donor mortality as high as 1 in 200 (Dew et al 2017: 881). Furthermore, in countries where access to dialysis is limited or prohibitively costly for much of the population and deceased donation programs are virtually nonexistent, as is the case in most parts of Africa and Asia, LDKT remains a life-saving opportunity for those with end stage kidney disease (ESKD) who can afford transplantation (Liyanage et al. 2015; Reese et al. 2015: 2004). However, LDTs are now widely practiced in the absence of life-saving necessity.

Many people with ESKD now have access to alternative life sustaining interventions such as dialysis, if not deceased donor transplants, yet living kidney donation has increased over time. LDKTs represented approximately 40 per cent of all kidney transplants performed worldwide in 2016, with more than 36.000 LDKTs reported to the Global Observatory on Donation Transplantation (2018: 2). In the absence of immediate high stakes in the form of life-saving necessity, determining the balance of risks and benefits that will justify living donation requires careful consideration of a range of potential outcomes of donation decision-making. In particular, it requires consideration of the prospective donor's potential interests in donation in the context of their relationships. Individuals are socially embedded and make decisions about donation in the context of relationships with family, friends and broader social communities. They also have longstanding roles and responsibilities that are influenced by and often enacted through interpersonal relationships. Hence, individuals may have "other-regarding" interests in donation in addition to personal welfare interests that should be considered when estimating potential benefits and risks of donation and of non-donation (Williams 2018: 19; Reese et al. 2018).

2.1 Risks and Burdens

In the early days of LDKT, despite the fact that there were few alternative treatments for people with ESKD, concern for donor wellbeing and uncertainty regarding risks underpinned a cautious approach. However, over time, the number of LDTs increased dramatically. This growth was in part influenced by the widespread perception that living kidney donation was a minimal risk activity. Comparison of the physical risks of donation with those of dangerous employment or leisure activities was often used in arguments that financial incentives could be offered to donors without fear of harmful exploitation (Cherry 2000: 343). The introduction of laparoscopic nephrectomy in the mid 1990s led to a decrease in perioperative morbidity associated with kidney donation and hence the immediate risk of harm to kidney donors has diminished considerably (Kok et al. 2006). However, the commonly cited risks of perioperative mortality (1 in 3000) and perioperative complications (1 in 6 donors) are not necessarily reflective of risks in all populations (Lentine et al. 2016). Increasing acceptance of higher risk donors, such as older people with comorbidities and obese donors has led to higher rates of both short and long term complications of donation (ibid).

A more dramatic shift in the level of risk considered acceptable in living donation was evident in the emergence of living liver donation during the 1990s. Abecassis and colleagues reported an overall incidence of complications associated with liver donation in the United States of 40 per cent, and a "1% incidence of residual disability, liver failure or death" (2012: 1216). The absence of alternative treatment for patients with end stage liver failure means that receiving a transplant is often a time critical matter of life and death. Initially considered acceptable when required to save the life of a child (Singer et al. 1989), living liver donation is now widespread despite the rate of perioperative complications. In the South East Asian region, limited availability of deceased donors means that LDs now supply more than 90 per cent of liver transplants (Global Observatory on Donation Transplantation 2018: 12). The total liver transplants from LDs per annum is estimated at 6012, or 19.8 per cent of total liver transplants worldwide (ibid).

Despite greater acceptance of significant risks to LDs in some contexts, it is the magnitude of the donor risk that usually sets the limit of what may be ethically permitted in a prospective LDT case, rather than the magnitude of the benefit that the recipient may gain from transplantation. Duties of beneficence to those in need of transplantation are thus trumped by obligations of nonmaleficence to potential donors. Evidence suggests this is consistent with the attitudes of clinicians, in particular surgeons, who may struggle with the burdens of responsibility involved in facilitating a major intervention that may be perceived as harming the healthy for the sake of the sick (Tong et al. 2013).

Harm to the donor is thus not considered a justifiable trade-off in return for improvements to the health of the recipient *per se*; in contrast to the more utilitarian framework of public health ethics, the separateness of persons is not overlooked in LDT ethics. In keeping with the traditional approach to clinical ethics, protecting and promoting the individual donor's welfare and interests ("benefits") are considered the primary duties of clinicians *vis a vis* prospective donors. In calculating the proportionality of potential benefits and risks of living donation, the potential benefits of transplantation for the intended recipient are effectively considered only in so far as they may be instrumental in producing benefits for the donor. The nature of risks and benefits that may be considered pertinent when determining whether a proposed LDT is ethically justifiable has also changed over time, as well as the relative value accorded to particular risks and benefits. While the immediate physical risks to the donor remain a primary concern, and the potential to save a life through transplantation is often a key priority, the longer term risks to donors both physically and psychosocially have assumed a greater importance together with the potential long-term psychosocial benefits of enabling a transplant – whether life-saving or not.

Despite widespread emphasis on the need for confidence in the assessment of risks and benefits of donation, several gaps in knowledge of risks and benefits persist, in particular with regards to outcomes in donor populations resident outside North America and Europe (Reese et al. 2015), longer term (>1 year) outcomes for living liver donors (Dew et al. 2017), and psychosocial outcomes that may be of particular interest to donors (Hanson et al. 2018).

Increasing awareness of the longer term impact of uninephrectomy on the health of LDs has fostered a renewed wave of caution with regards to living kidney donation, particularly in the light of evidence indicating that donors are at a higher relative risk for renal failure (Maggiore et al. 2017). Risk stratification has revealed that some donors have a much higher risk than others (Lentine et al. 2016). Nephrologists and transplant surgeons commonly cite the risks of kidney donation as a primary concern, particularly when dealing with younger donors for whom risk evaluation is less certain (Tong et al. 2013; Steiner 2019).

Potential psychosocial burdens of living donation are also increasingly recognized as relevant considerations (Delmonico 2005; Barr et al. 2006), although there has been comparatively little research investigating the psychological and non-economic social impact of donation. Much of the research in this field has been conducted in America. Accordingly, there is little evidence-based guidance available to facilitate risk assessment of prospective donors in their local socioeconomic and cultural context, and psychosocial screening is neither standardized nor routinely performed even in high income countries (Anderson et al. 2007; Massey et al. 2018). Nevertheless, the results of American research provide valuable insights into ethical considerations of relevance around the world. For example, the impact of lost income experienced by American donors is likely to be exacerbated in the context of donors living in low income countries in which even the basic protections of social welfare available in the United States may be lacking.

LDs may suffer significant financial harms as a result of taking time off work to donate, and in some cases may be required to cover the costs of evaluation as a donor (Delmonico et al. 2015; Dew and Jacobs 2012; DiMartini et al. 2017). Their ability to access follow up care to protect against longer term health risks, particularly in the context of kidney donation, may be conditional upon their financial situation. Donors may also experience higher health insurance costs (Dew and Jacobs 2012; Dimartini et al 2017). In recent years efforts have been made to evaluate and address the financial risks of donation in several high income countries, including Australia, the United States, and several European countries, for example through governmental programs providing paid leave for donors and coverage of costs associated with donation (Hays et al. 2016).

Studies suggest that while donation generally has a positive psychosocial impact on donors, some donors may suffer from depression or anxiety, and donation may negatively impact on relationships with their recipient and/or family (Lentine et al. 2019; Timmerman et al. 2016). Concern for the psychosocial risks of donation has primarily focused on those of unrelated donors for whom guidelines have been developed and for whom psychosocial screening is routinely performed (Dew et al. 2007). This may reflect assumptions that such donors may be more likely to have a psychological disorder and perhaps the belief that the potential benefits of donation are diminished in the absence of a close relationship between donors and recipients, thus entailing greater concern to ensure that psychosocial risks are minimized.

2.2 Benefits and Interests

The multifaceted potential benefits of donation for the LD herself are now well recognized. These may include the emotional and psychological benefits of helping others such as improved self-esteem, as well as the positive impact of transplantation on a relationship and/or family by greatly improving an individual's health and/or preserving their life (Leventine et al. 2017, Schulz et al. 2009; Erim et al. 2007, Clemens et al. 2006). Although the immediate stakes of living kidney donation decision-making may be less compelling in so far as the ethical imperative to save a life is concerned, LKDTs may offer significant advantages for recipients (and hence indirectly to donors) compared with transplants from deceased donors or dialysis, particularly when considered in the longer term. The relative benefits of living compared with deceased donor kidney transplants may be somewhat overstated, as it is often those who are in better health and socioeconomically advantaged who are able to access a LDT and avoid time on dialysis that may undermine their health in the longer term (Schold et al. 2018). However compared with dialysis, LKDTs generally provide far better health and psychosocial outcomes for most people with ESKD. In addition to survival gains, quality of life is greater and costs of ongoing care are lower. LD liver transplants also presently offer health advantages for recipients when compared with deceased donor transplants (Montenovo et al. 2019). Improved health may enable recipients to assume roles within the family that are beneficial to the donor, for example by returning to work and/or being able to fulfill parenting duties and so on.

A key benefit of kidney or liver donation is also the avoidance of what may reasonably be assumed a significant harm to most prospective donors, namely the death of a loved one or their continued reliance on dialysis. Very little is known of the potential risks of declining a prospective LD candidate, although recent research suggests some declined donor candidates may suffer psychosocial harm (Jennings et al. 2013; Reese et al. 2018). It is conceivable that in some cases, the potential negative impact of missing the opportunity to preserve the life of a loved one may cause greater harm in the longer term than would have occurred if a higher risk donor had been permitted to proceed. Such risks may include guilt at failure to be approved, or anger or regret that they were denied the opportunity to donate (Allen et al. 2014; Jennings et al. 2013).

2.3 Risks and Benefits in the Context of Relationships

Many of the psychosocial risks and benefits described above are largely premised on the assumption of a close relationship between the LD and the transplant recipient. Early donors were usually identical twins, and then parents of children, due to the need for close genetic matching and the belief that for parents or twins the loss of a child or twin was a sufficiently great harm to balance the potential risks of donation. Spouses were soon accepted as donors, and over time, in addition to biologically related donors and spousal donors, acceptance of so-called "emotionally related" donation has emerged which includes more distant familial relationships, friends and even social acquaintances in some transplant programs (Spital 2000). The depth and nature of relationships between prospective donors and recipients have implications for the assessment of risks and benefits as well as the voluntariness of donation. Closer relationships may offer more benefits to the donor as the positive impact of transplantation on recipient health can improve the donor's own life and family wellbeing. The intimacy of a loving relationship between donor and recipient also means the harm avoided when transplantation prevents loss of life is proportionately greater (Van Pilsum Rasmussen et al. 2017). Closer relationships may also reduce concerns that the motivation for donation may be due to problematic factors such as a coercive influence, or desire for personal fame or emotional reward from the recipient as it is often discussed in unspecified living organ donation (see chapter 8 in this book). On the other hand, closer relationships may also be coercive with multiple ties binding the donor to a potential recipient such that they feel they have no option but to donate to preserve the breadwinner of a family or under pressure from other relatives (Wöhlke 2017).

3. Consent for Donation Decision-Making

Considerable attention has been given to concerns regarding the validity of consent to become a LD. Several factors may be considered to undermine the quality of prospective donor decision-making and/or the validity of their consent, which requires the donor to be competent to make a decision, sufficiently informed, and able to make a voluntary decision free of coercion, deception or manipulation. As noted above, the limited availability of robust evidence regarding longer term risks and benefits of donation – as well as those associated with a decision not to donate – may undermine the ability of prospective donors to make a fully informed decision. Living kidney donation might ideally be deferred, for example, until prospective donors are middle aged, to enable a more accurate assessment of their lifetime risk of renal disease (Steiner 2019). Nevertheless, ethical concerns about consent for donation predominantly focus on questions of competency and voluntariness.

3.1 Competency to Consent

Arguably, many prospective donors might lack the ability to make a fully rational and considered decision about donation. Faced with a loved one's need for transplantation, many donors have reported making an impulsive decision to donate prior to receipt and processing of relevant information about donation (Papachristou et al. 2010). Concerns that internal or self-imposed pressures to donate are unduly influencing decision-making or undermining the quality of decision-making are in part addressed by strategies such as rigorous psychosocial evaluation, use of 'cooling off' periods for decision-making and of LD advocates (ibid.; Gordon et al. 2015).

Potential donors who may have limited decision-making capacity – as the term generally applies to medical decision-making – include children or adolescents below the legal age of majority and individuals with cognitive impairments or mental illness that may temporarily or permanently undermine their ability to weigh the relevant information and form an enduring decision about donation in accordance with their own values, beliefs and preferences. In some countries, legal minors or adults lacking legal competency to make their own decisions are excluded from living donation programs (Thys et al. 2013; Thys et al. 2016). In others, they may be permitted to donate if judged competent to consent to donation, or if they assent to a donation that has been authorised by their legal guardian (ibid). In its *Guiding Principles on Human Cell, Tissue and Organ Transplantation*, the World Health Organization (WHO) notes that where donation by a legally incompetent person is legally permitted, "Specific measures should be in place to protect" the donor (Sixty-Third World Health Assembly 2010: 8). The WHO suggests that such donations should only occur in exceptional circumstances (ibid.: 9).

3.2 Voluntariness in the Context of Donor Relationships

Concerns relating to the decision-making capacity of a prospective donor are often intertwined with concerns regarding voluntariness; understandably, those who may lack decision-making capacity are often at the greatest risk of exploitation or coercion (Van Assche et al. 2014). Biller-Andorno (2011) notes that a donor's autonomy may be under threat if there is coercion, or pressure intentionally exerted by others to compel a donation decision, but also by virtue of the fact that autonomy and decision-making are inherently relational. Family members or close friends, for example, may often influence and inform important decisions that individuals make, particularly when they have a shared interest in the decision being made (Verkerk et al. 2015) as is the case in living donation (Wöhlke 2017). In the context of related donation, concerns regarding potential conflicts of interest in decision-making may be difficult to address without isolating the prospective donor from the customary supports they would have when making important decisions in their lives. Baylis et al. observe that "rather than pretending that individuals can make decisions 'free' of outside influences, relational autonomy encourages us to pay close attention to the types of forces that may shape an individual's decisions" (2008: 202). Thus Biller-Andorno (2011) argues that understanding the many factors that may undermine donor autonomy and assessing these effectively during evaluation of prospective donors is essential, as is implementation of safeguards to protect the donor from undue influence and to ensure their freedom to refuse donation. Accordingly, independent donor advocates are recommended in the United States to help ensure that donors are making a competent and voluntary decision (Hays et al. 2015). Other strategies that may be implemented to protect the autonomy of prospective donors include provision of a medical "alibi" that may be used as a reason for donation to be declined instead of disclosing the prospective donor's refusal to donate (Thiessen et al. 2015b).

In some countries, concerns about external coercion of prospective donors rather than internal factors or impaired decision-making capacity may predominate. Familial or sociocultural hierarchies and values in some communities may directly or indirectly exert pressure on individuals to donate. For example, women may be expected to donate for the benefit of spouses, children or male siblings because of their perceived role as a caregiver or lower instrumental value to the family (Scheper-Hughes 2007). Gender disparities in rates of living kidney donation and transplantation are well described, although higher rates of female donation and lower rates of LKDTs in females in some countries are not wholly attributable to gender norms or bias influencing consent or even donor selection (Carrero et al 2018; Gill et al 2018). In other contexts, concerns about the voluntariness of donation may focus on risk factors for human trafficking, particularly in countries with large economically vulnerable populations such as India or Pakistan (see chapter 11). The socioeconomic status of prospective donors, and the comparative status of their intended recipient, for example, may indicate potentially coercive relationships, irrespective of potential familial or social relationships. Prospective donors and recipients who travel abroad for transplantation despite the existence of programs in their own country may also raise suspicion of human trafficking for the purpose of organ removal (Domínguez-Gil et al. 2018).

4. Paternalism

While greater efforts to detect and prevent coercion and to optimize the quality of informed and voluntary decision-making by prospective donors are needed, concerns regarding the autonomy of donation decision-making are likely to persist. To some extent, these concerns reflect the habitual challenges of decision-making in health care more generally; often patients are required to select from a limited range of imperfect options for treatment of serious conditions, each with risks and potential benefits that may be difficult to assess. The ethical stakes of donation decision-making however, may be considered greater, given the greater potential for conflicts of interest that may influence decision-making and the fundamental problem that any donation imposes some degree of physical risk to the donor that cannot be offset by the usual justification that intervention of some kind may be therapeutically necessary, as is the case for an ordinary patient. Unsurprisingly, questions regarding the autonomy of a prospective donor's decision may therefore be used to justify a degree of paternalism that may be considered unacceptable in the normal setting of health care decision-making.

4.1 Acceptance of Risk is a Right of Competent Persons in Health Care

Respect for autonomy has widely assumed a primary position in ethical decision-making in clinical practice. When an adult is ill or injured, if she is deemed competent to make informed decisions for herself, then she is permitted to refuse even life-saving treatment, and to choose between available options in accordance with her own values, beliefs and preferences. When more than one treatment option is available, the competent patient herself is usually considered best placed to evaluate the potential risks and benefits in the context of their own life, particularly as these usually entail qualitative judgements and personal preferences regarding the assumption of risk. It is the place of health professionals to support such decision-making, and to identify the options that should be considered. For example, interventions that are deemed to have no evidence base for success in a particular case may be considered futile and are hence not offered – particularly if they have associated risks or costs. Although some procedures may offer uncertain benefits, have a relatively low probability of success, and/or carry significant risks, these are often still presented as options, particularly in the absence of alternatives with a better risk-benefit profile or when they offer a chance – however small - of restoring vital functions or prolonging life. Thus, people may undergo experimental cancer treatments or risky surgical procedures in life or death situations.

4.2 Clinician Involvement in the Setting of Risk Thresholds for Donation

While clinicians play a leading role in determining the range of therapeutic options that may reasonably be offered to a patient, there appears to be greater scope for clinicians to apply their own value judgements regarding proportionality of risks and benefits for a prospective LD. This is significant given research indicating that transplant professionals are more risk averse that prospective LDs (Young et al. 2008). Spital (2004: 107) observes that, "it is the potential donor herself who is best able to determine if the expected benefits are worth the risks. On the other hand, physicians must make their own assessments, and they should never be forced to perform a procedure that they think will do more harm than good."

Thus, whereas patients are routinely permitted to undergo invasive procedures with high risk of short and/or long term harms in the hope of achieving a therapeutic benefit, prospective donors may be declined with an equivalent or more favorable risk-benefit profile simply because the clinical benefit will accrue to the transplant recipient rather than the donor herself.

In defining the limits of acceptable risk for living donation, there is general consensus that donation should not be likely to cause the death of the donor. Further, the anticipated gain in health for the recipient should be greater than the anticipated loss of health for the donor. (Authors for the live organ donor consensus group 2000: 2924)

Despite such principles, and frequent references to the importance of benefits for the donor outweighing the risks, there is considerable scope for disagreement regarding the proportionality of risks and benefits that would fall within the "reasonable" range considered acceptable by clinicians. Donors who lack life time health insurance are frequently accepted in some countries, such as the Philippines or India, despite the risk they may be unable to access long term follow up care in the event of complications, whereas such coverage is a necessary condition for donation in others. In South Korea, adolescents are not infrequently accepted as living liver donors from the age of 16 (if donating to a parent), (Hwang et al 2006) whereas this is considered unacceptable in European countries (Thys et al. 2016). There is evidence of considerable variation in practice across transplant programs, even within countries, with regards to criteria used to evaluate donor risk and determine when to exclude prospective donors (Gabolde et al. 2001; Rodrigue et al. 2007; Thiessen et al. 2015a).

Variation in guidelines and practice around the world and within countries is to be expected, given risks and potential benefits of living donation will be influenced not only by factors specific to particular donor and recipient populations but also by factors specific to the local health care context. The level of experience and expertise within specific transplant programs may, for example, influence the risk of surgical complications for particular procedures. Nevertheless, clinician assessments of proportionality in risks and benefits may be subject to cognitive biases, personal values and beliefs, and/or conflicts of interest that may influence their acceptance or refusal of potential donors. Financial interests might, for example encourage the acceptance of higher risk donors in order to enable lucrative transplants to be performed, or alternatively encourage risk avoidance for fear of impairing quality indicators associated with clinician or institutional reputations.

4.3 Balancing Patient Autonomy and Moral Agency of Transplant Professionals

Thiessen and colleagues (2015a: 2315) advocate a donor-centered approach to risk assessment that would give greater weight to prospective donor values and preferences when dealing with "discretionary donors", that is, "medically complex" donors with a slightly higher level of risk who nevertheless wish to proceed with donation despite potential disagreement regarding the acceptability of risk from clinicians. While helpful in resolving some potential conflicts between respect for donor autonomy and the clinician's duty of nonmaleficence, this approach is unlikely to resolve all disagreements between prospective donors and clinicians regarding acceptable risk thresholds or proportionality of risks and benefits. In such cases, several authors have defended the clinician's right to decline a donor. (Authors for the live organ donor consensus group 2000: 2925) Ross and Thistlethwaite argue that to proceed otherwise would be unethical: "the members of the transplant team are moral agents who must concur that the risks and benefit: risk to both parties individually and jointly is reasonable or they should refuse to proceed with performing the living donor surgery" (2018: 844).

In such cases, however, how might the risks of undue paternalism or bias in clinical risk assessment for prospective donors – and their intended transplant recipients – be managed? Paternalistic decision-making is most likely to affect populations that already suffer from exclusion and poorer health outcomes in the setting of donation and transplantation. For example, African Americans and Indigenous prospective donors are more likely to have a higher risk profile, and their intended recipients are also more likely to miss out on deceased donor transplants (Reese et al. 2015). Reluctance to accept donors from these populations may have a significant impact on equity in transplantation.

One partial solution is to promote transparency in clinical decision-making and routine reporting of outcomes of prospective donor assessment, to enable evaluation of transplant center decision-making. Alternatively, one might treat such cases as a form of conscientious objection by health professionals. The right of conscientious objection allows clinicians to refuse to provide a clinical intervention that is legal and would be considered clinically appropriate by professional peers, on the grounds that providing such an intervention would violate the clinician's personal moral values and beliefs. At least some decisions to decline a prospective donor on the grounds that the expected risks of donation are disproportionate should be recognized as reflecting a clinician's personal judgment that to proceed with donation would be ethically unjustified, whereas another clinician may find the risk-benefit ratio within the range of reasonable options to be chosen at the discretion of prospective donors.

The controversial right to conscientious objection is often deemed conditional, in order to minimize inequities in access to care for patients and to prevent serious harm to patients. For example the right may not be exercised in an emergency setting when refusal of treatment would endanger the patient, and it may be associated with an obligation to inform the patient of alternative opportunities to receive the intervention in question, if not refer the patient to a clinician willing to provide the intervention. If disagreements regarding acceptable risk thresholds and proportionality of risks and benefits are regarded as a matter of conflicting ethical values rather than tension between the autonomy of prospective donors and that of clinicians, this may facilitate a more constructive response in the event of some decisions to decline prospective donors. Clinicians or transplant centers might be encouraged to refer donors to alternative care providers for a new assessment, for example, rather than treating an assessment as a conclusive judgment regarding donor suitability.

5. Conclusion

The perennial issues of proportionality in risks and benefits of donation and limits of prospective donor autonomy are regularly invigorated by the emergence of novel procedures and policies, and experimentation by clinicians willing to test the boundaries of accepted practice. Various populations of 'marginal risk' donors and recipients, such as those of older age (see chapter 12 in this book), have gradually become established in some settings. Most recently, an HIV-positive woman donated part of her liver to her daughter, in a transplant justified on the grounds of life-saving necessity given that the child had no prospect of receiving a suitable organ from a deceased donor or from an HIV-negative LD (Botha et al. 2018). Specific types and novel forms of directed living donation, such as paired kidney exchanges, transorgan paired exchanges and advanced donation programs have also presented new ethical dilemmas, or significant variations on longstanding ethical concerns (Kranenburg et al. 2004; Fortin 2013; Samstein et al. 2018; Martin/Danovitch 2017).

The field of living organ donation situates familiar ethical dilemmas of clinical practice, namely tensions between physician duties of beneficence and nonmaleficence and respect for patient autonomy, in a particularly challenging context. The physician customarily has the comfort of therapeutic necessity when performing a potentially harmful procedure on a patient. In living donation, exposing the healthy donor to harm requires a significant shift in the framing and evaluation of risks and benefits of clinical interventions. In this context, the duty of beneficence is perhaps best understood not as an obligation to address a deficit in the patient-donor's health status, but rather to help them to address an actual or foreseeable deficit in their broader well-being, or simply to enhance their wellbeing by enabling them to fulfil a personal goal of donation. This approach is not, in theory, dissimilar from ethical decision-making in clinical practice in the non-transplant context. Determining whether an intervention is in the best interests of a patient requires careful attention not only to their physical or psychological health but also to their complex and varied life goals, values and preferences which are shaped by interpersonal relationships, experiences and broader interests.

As more information emerges regarding LD risks and potential benefits in particular populations and contexts, and new practices are introduced that challenge the values we place on specific types of risks and benefits and disrupt traditional frameworks for decision-making and consent, ethical analysis of LDT should provide ongoing opportunities for reflection on the ethical standards we apply in clinical practice more generally. As we question, for example, the limits of physician paternalism in LDT, we should be prompted to explore potential paternalism in other contexts. Is it possible that similar values and concerns influence – explicitly or not – the range of therapeutic options deemed 'reasonable' for patients in other contexts? Research investigating living organ donation sheds invaluable light on the relational nature of individual autonomy and of benefits and harms, and on the way that broader socioeconomic and cultural factors may shape – both positively and negatively - opportunities for health care and health outcomes. Rather than challenging the ethical values and principles that are espoused in health care policy and practice, LDTs should challenge us to think critically about the way these values and principles are applied in practice across our health care systems.

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