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Chapter 30

GENDER INEQUITIES IN ORGAN DONATION AND TRANSPLANTATION

A feminist bioethics analysis

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Introduction

Organ transplantation is one of the success stories of modern medicine. Failing livers, kidneys, hearts, lungs and other organs are routinely replaced with organs from living or deceased donors. For some recipients, transplantation offers freedom from onerous treatments like renal dialysis or ventricular assist devices. For heart or liver recipients, transplantation literally offers a new lease of life. Since the development of effective immunosuppressant drugs in the 1960s, the global number of transplantations has risen annually, from 41,259 in 2000 to 163,138 in 2019 (GODT 2021). Despite these increases, many thousands of people remain on waiting lists as current transplantation rates meet little over 10% of estimated worldwide need (GODT 2017: 7). This mismatch between available organs and the number of patients who could benefit from transplantation is the defining feature of transplantation ethics, raising questions about ethically justifiable methods for increasing organ supply, and the equitable distribution of the scarce organs that are donated.

Sex and gender intersect with this central ethical dilemma of scarcity in multiple ways. There are differences between men and women in rates of organ donation, in transplant waitlisting and in outcomes. As well as these gendered patterns, the benefits of donation and transplantation vary along other axes of power and disadvantage, such as race and geo-political location. These differences are starkest in relation to organ trafficking, reflecting the links between poverty, powerlessness and exploitation within and between nations. In its most horrific form, forced organ harvesting has been linked to some of the worst human rights abuses of the twenty-first century (China Tribunal 2020).

Transplantation differences between women and men have been attributed to a variety of biological, genetic, socio-cultural and gendered factors. Within the transplantation literature, analyses often appeal to gendered stereotypes, such as those of women's alleged altruism or affinity with the role of family caregiver (see e.g. Teegen et al. 2016; Mihçioğur et al. 2019). Other analyses focus on the complex interplay of biological and genetic factors affecting disease incidence, or gendered behaviors that increase men's chances of becoming deceased donors (see e.g. Puoti et al. 2016; Melk et al. 2019). My approach is grounded in the view that both social and biological factors contribute to variations in organ donation and transplantation between women and men, with a focus on determining which variations are inequitable.

This chapter focuses on the ethics of sex and gender differences arising from solid organ donation and transplantation. The first section of the chapter synthesizes recent empirical data on organ donation and transplantation to illustrate the complex relationships that pertain among sex, gender, donation and transplantation. This process reveals patterns of gender-related inequities and associated biomedical and social explanations.¹ Within this biomedical literature, the need for and benefits of organ donation are taken for granted. The challenges are understood in terms of making the existing system work more equitably where there is obvious sex/gender discrimination, with the aim of women achieving parity with men regarding donation rates, access to transplantation and outcomes. The second section offers a feminist critique. The feminist approach looks beyond current arrangements to analyze organ donation and transplantation as practices located within social systems and structures that affect women and men differently, in ways that are inflected by power relations. My analysis focuses on four areas of feminist scholarship: the sacrificial framing of organ donation, embodiment, care ethics and women in research. I argue that the feminist approach offers conceptual insights into gender differences, casting new light on ethical issues.

Gendered patterns in donation and transplantation

The relationship between sex and gender in transplantation medicine is complex. Despite sex and gender being important factors affecting all aspects of donation and transplantation, they are rarely the main objective of relevant research or even reported at all, and the concepts are often used interchangeably (Laprise et al. 2019). The Global Observatory on Organ Donation and Transplantation (GODT) is a leading repository of international data on donation and transplantation rates, yet did not include data on gender until 2017: “As a *novelty*, information about the gender data is presented for first time in the annual report” (2017: 48, emphasis added). The lack of detailed reporting correlates with gaps in information about gendered patterns of organ donation and receipt. Recent global data shows that 63% of organ recipients worldwide are men (GODT 2017: 44). The situation is more nuanced regarding donors. More living donors are women (at 53%) than men, but this is reversed for deceased donors, 60% of whom are men (GODT 2017: 46). The impact of sex and gender varies by type of organ and type of donation (living or deceased), requiring detailed scrutiny to identify sex and gender-linked differences and potential inequities. In addition, geo-political and other socio-demographic variables such as racialized group, ethnicity and socio-economic class, intersect with sex and gender creating a complex web of overlapping gender-linked differences, some of which are inequitable. Here my discussion focuses on kidneys, livers and hearts as these are the commonest solid organs transplantations. Kidneys comprise 65% of all transplants, livers 23% and hearts 6% (GODT 2017: 7).

Organ donation

Worldwide, the majority of organs for transplantation are procured after death, from individuals who die in circumstances compatible with organ retrieval. Individuals who wish to be deceased donors can register as such in many countries, with slightly more women (54%) than men registering overall (Jones et al. 2019). If a potential donor is not registered, a family member may grant permission for donation. The donation decision must be made within a timeframe dictated by the need to rapidly procure organs, while dealing with the stress of the potential donor’s imminent or actual death.

There are more male (60%) than female deceased donors (GODT 2017: 45), because more men die in the relevant circumstances. The commonest causes of donor death are strokes, trauma

and anoxic brain damage from drug overdoses or drowning (Hassanain et al. 2016). Trauma is a commoner cause of death in men than women (CDC 2017). While more women than men die of stroke (AIHW 2020), this is generally at an older age. As organ quality deteriorates with age, women dying of strokes are less likely to become donors than men. Reflecting the greater number of male donors, decisions about donation often fall to mothers or female partners, a point taken up in the second part of this chapter.

Living donation is the other source of transplantation organs. Healthy individuals may donate one kidney, or part of their liver (known as split liver donation). Living kidney donors have the same life expectancy as non-donors (Kim et al. 2020). Split liver donors have a small increased risk of dying and up to one third may experience surgical complications (Lieber, Schiano and Rhodes 2018). At a global level, slightly more women (52.5%) than men are living donors (GODT 2017: 46).

There are two different gendered patterns of voluntary living donations. In Western countries where deceased donation dominates, women have a higher incidence of living donation than men. For example, in the USA in 2020, 64% of living donors were female (OPTN 2021). Women are more likely than men to donate to their spouses; of suitable potential donors who donated a kidney to their respective spouses, 36% were women, but only 6.5% were men (Teegen et al. 2016). In contrast, men outnumber women as living donors in countries without well-established deceased donor programs such as Korea, Japan and Turkey. In these countries, living donation is the primary source of organs with men comprising around 60% of donors (GODT 2017; Yankol et al. 2020). Iran is the only country where paid organ donation is legal. There 81% of paid unrelated donors are men while women provide 65% of unpaid living-related donations (Fallahzadeh et al. 2013).

Most living organ donations are voluntary, but around 10% of all transplantations come from illegally trafficked organs bought and sold on the black market (Mavrellis 2017). The majority of individuals whose organs are trafficked are men, but accurate data are lacking (Naqvi et al. 2007; Forum for Protection of People's Rights Nepal 2015; Lundin 2015). The People's Republic of China is unique in systematically trafficking organs from deceased individuals, obtained from killing prisoners of conscience (China Tribunal 2020). There are no reliable demographic data on the victims but the majority may be male, reflecting a Chinese belief that organs from men in their late twenties are optimal for transplantation (*Searching for the "Disappeared,"* at 3:46 min.).

How can we make sense of these different donation patterns, in terms of sex and gender? Some of the differences have biological origins, such as age of death. Women tend to live longer than men, and men have higher rates of cardiovascular disease causing sudden death (Puoti et al. 2016). However, men dying at younger ages than women reflect gendered patterns of risk taking and healthcare utilization as well as biological differences. Female gender norms are invoked to explain higher rates of living kidney donation in Western women. Potential reasons include that women feel more responsibility for family members' health, can more easily take time off due to their part-time or lowly paid employment, are more self-sacrificing and altruistic than men, or more susceptible to coercion (Puoti et al. 2016; Teegen et al. 2016; Miñçokur et al. 2019). Gendered norms pull in a different direction when there is pressure within families for men to be living liver donors. Pressures arise from the perceived obligations of sons to help their fathers, the need for a female carer in the family to look after both donor and recipient, or the potential damage to the marriage prospects of young women posed by a liver donation scar (Lin et al. 2021). Likewise, gendered norms around financial responsibility put pressure on men to raise money by selling an organ (Forum for Protection of People's Rights Nepal 2015). In summary, both sex and gender influence who seeks to be a deceased donor, who dies in the relevant circumstances, whose organs are suitable for transplantation, and who makes a commercial or voluntary living donation.

Diagnosis and waitlisting for transplantation

The first step in transplantation is diagnosis with the relevant disorder. Rates of organ failure diagnosis differ between men and women for social and biological reasons including epigenetic, genetic, endocrine, environmental, social, economic and behavioral (Wainer et al. 2020). Men have higher rates of, and are more likely than women to be diagnosed with diseases such as end-stage renal disease (ESRD) and cirrhosis and hepatocellular carcinoma that lead to kidney and liver transplantation respectively (Teegen et al. 2016; Melk et al. 2019; Mihçioğur et al. 2019). The picture with heart disease is more complicated. Coronary heart disease is commoner in men (Bots, Peters and Woodward 2017), but there are relatively similar prevalence rates of heart failure (a leading indication for transplantation) in men and women (Regitz-Zagrosek et al. 2010).

Reflecting higher rates of disease, more men than women will be admitted to transplantation waiting lists. For equity, men and women with equal severity of disease should be listed at the same rates. However, there is a dearth of relevant high-quality contemporary data to assess whether equity is achieved (Melk et al. 2019). What data there are show differences between organs, summarized in Table 30.1.

As Table 30.1 shows, various biological and social factors affect diagnosis and waitlisting. Regarding liver failure, the equitable listing of women was secured following adoption of a liver failure scoring system known as MELD (Model for End-stage Liver Disease) that explicitly aimed to increase transparency, objectivity and equity (Melk et al. 2019). The picture is bleaker regarding listing for heart transplantation where there is significant inequity for women, related to discrimination by physicians as well as lack of advocacy by and for women. For example, a German study found that only 15% of patients with dilated cardiomyopathy referred for transplantation were women despite the condition affecting equal numbers of men and women. Women who were

Table 30.1 Biological and social factors affecting women's access to transplantation wait lists

<i>Organ</i>	<i>What is known about access to wait list</i>	<i>Biological explanatory factors</i>	<i>Social explanatory factors</i>
Liver	Equal between men and women with same disease severity	<ul style="list-style-type: none"> • N/A 	<ul style="list-style-type: none"> • Adoption of scoring system (MELD) to address previous inequity
Heart	Lower for women with equal disease severity	<ul style="list-style-type: none"> • Lower overall rates of heart disease 	<ul style="list-style-type: none"> • Lower rates of investigation of women, with fewer referrals and less encouragement for transplantation from doctors • Fewer social supports for women, including lack of partner support in consultation • Women's higher rates of-refusing transplantation
Kidney	Lower for women with equal disease severity	<ul style="list-style-type: none"> • Immunological factors including pregnancy-related sensitization that preclude transplantation • Slower loss of renal function due to protective effects of estrogen 	<ul style="list-style-type: none"> • Lower rates of investigation of women and less discussion of transplantation as an option • Women's greater physical and psychosocial concerns about transplantation • Women's lack of confidence in asking about transplantation

referred were sicker than their male counterparts. The discrepancy was attributed to social factors as per Table 30.1 (Regitz-Zagrosek et al. 2010).

ESRD is commoner in men, but there are few studies comparing waitlist access of transplant-eligible men and women with similar severity of disease, making it difficult to determine any inequities (Melk et al. 2019). However, recent evidence from Australia and Europe shows that women are 15% less likely than men to be waitlisted for deceased donor kidney transplantation (Melk et al. 2019; Sypek et al. 2019), for social and biological reasons (Teegen et al. 2016; Melk et al. 2019).

Receiving an organ

Once onto a waiting list, further sex and gender-related differences arise, which again vary by organ (see Table 30.2).

Paradoxically, the MELD scoring system that leads to equitable listing of women for liver transplantation has the opposite effect when it comes to receiving an organ. This is because MELD scores include the creatinine level, which is used as a proxy for renal function (which is relevant for liver transplant outcomes). Due to sex-linked variations in creatinine, reflecting differing male and female muscle mass, women have a lower MELD score than men with same level of renal function. This leads to inequity as women with an equal need for liver transplant are scored as less urgent than their male counterparts. Physical size is also an issue because the majority of deceased donor livers come from men and are allocated to men as they are too big for female recipients. Smaller organs or split livers that are the correct size for women may be preferentially allocated to children (Sakar et al. 2015). Finally, female sex is an independent risk factor for being delisted for being too sick (Cullaro, Sarkar and Lai 2018).

Approximately 25% of heart transplant recipients are female, reflecting their proportion on the wait list (Walters et al. 2020). Once listed, women are transplanted more quickly than men often because they are sicker and/or willing to accept a non-optimal organ (Regitz-Zagrosek et al. 2010).

The situation regarding kidneys is complex. Women on kidney waitlists are approximately as likely as men to receive a kidney, but there are patterns of inequity as older women and women classified as overweight or obese (body mass index [BMI] greater than 25 kg/m²) are less likely to

Table 30.2 Biological and social factors affecting women’s chances of receiving an organ once onto the waitlist

<i>Organ</i>	<i>Chance of receiving an organ once on the waitlist</i>	<i>Biological factors</i>	<i>Social factors</i>
Liver	Women 30% less likely	<ul style="list-style-type: none"> • MELD score • Physical size 	<ul style="list-style-type: none"> • Non-specific gender discrimination
Heart	Women have equal chance	<ul style="list-style-type: none"> • Women sicker than men at time of transplant 	<ul style="list-style-type: none"> • Women more likely to accept non-optimal organ • Men more likely to use ventricular assist devices
Kidney	Overall women have equal chance of transplantation but: <ul style="list-style-type: none"> • less chance of receiving living donor organ • less chance of transplantation if over sixty-five or classified as overweight or obese (see below) 	<ul style="list-style-type: none"> • Higher incidence in women of antibodies or autoimmune disease 	<ul style="list-style-type: none"> • Reluctance by women to ask relatives for living donation • Physician bias against heavier female patients

be transplanted than men who are relevantly similar. In contrast, men who are overweight or have class I obesity (BMI between 25 and 35 kg/m²) have facilitated access; men’s access decreases only when their BMI exceeds 40 kg/m² (Gill et al. 2014). While increasing BMI is linked to poorer transplantation outcomes, gender bias seems to be a factor in excluding women at lower BMIs than men. Women are less likely than men to receive living kidney donations, due to biological factors as well as hesitance in asking for living-related donation (Melk et al. 2019). As with waitlisting, a variety of factors affect the likelihood of receiving an organ, at least some of which are due to unfair gender discrimination.

Transplantation outcomes

Transplantation outcomes are measured by years of survival of either the graft (transplanted organ) or the patient. Biological and social factors affect outcomes, leading to various differences for women and men. Organ quality can be affected by donor sex, through factors including organ size, differences in regenerative capacity, susceptibility to physiological stress and presence of antigens. Female deceased donors tend to be older than male donors and have poorer quality organs than young male donors (Puoti et al. 2016; Walters et al. 2020). On the recipient side, women tend to produce more vigorous immune reactions mediated by estrogens, resulting in higher rates of rejection (Melk et al. 2019). In contrast, testosterone suppresses some immune functions, thereby protecting transplantations (Sakar et al. 2015). Immune function is moderated by age and menopausal status; older women have improved graft survival compared to younger women. Sex matching of organ and recipient is a further factor complicating graft survival, with variable effects of different sex-organ pairings for each organ. There are sex differences in the metabolism of anti-rejection drugs, with women being at higher risk of adverse events from some agents (Melk et al. 2019). Social factors affecting outcomes include degree of adherence to anti-rejection drugs, compliance with follow-up regimes and behavior changes to protect graft function. In general, women are more compliant with care regimes and have better medication adherence than men (Puoti et al. 2016; Melk et al. 2019). The organ specific factors affecting outcomes are summarized in Table 30.3.

This detailed examination of sex and gender differences in organ donation and transplantation illustrates the complex factors affecting who gets ill, who becomes a donor, who receives an organ and how they fare post transplantation. The level of detail points to the need for careful analysis to identify gender-related inequities and how these might be addressed. To some extent, these

Table 30.3 Biological and social factors affecting women’s survival and organ function after transplantation

<i>Organ</i>	<i>Transplant outcome (survival and organ function)</i>	<i>Biological factors</i>	<i>Social factors</i>
Liver	Women have equal outcomes	<ul style="list-style-type: none"> • Men more likely to be weaned off immunosuppressants 	<ul style="list-style-type: none"> • Women report poorer quality of life
Heart	Women have equal outcomes	<ul style="list-style-type: none"> • Post-menopausal women and women receiving male hearts have best outcomes 	<ul style="list-style-type: none"> • Women report worse functional ability • Women more adherent to medications
Kidney	No agreement as to whether there are equal outcomes for men and women	<ul style="list-style-type: none"> • Women have higher rates of acute rejection but lower rates of chronic rejection • Male grafts have the best function 	<ul style="list-style-type: none"> • Married men have better graft survival but not married women • Women more adherent to medications

analyses are already taking place in the transplantation literature (see e.g. Puoti et al. 2016; Teegen et al. 2016; Melk et al. 2019). What I hope to show in the remainder of the chapter is how feminist bioethics can bring novel conceptual insights to the analysis of gender inequities and other ethical issues in organ donation and transplantation.

Feminist analyses of organ donation and transplantation

Within the transplantation literature, gender equity is understood in terms of women achieving parity with men regarding donation rates, waitlisting, transplantation and survival of both recipients and their grafts. In this section, I focus on organ donation and transplantation from a feminist perspective. This approach interrogates the lived experiences of those who give and receive organs, recognizing the physicality of the practices, their effects on embodiment and the particularity of each act of donation and transplantation within existing relationships of power. I take up four specific feminist themes: the sacrificial framing of organ donation; embodiment; care ethics; and women in research.

Gift, sacrifice and justice

Organ transplantation occupies a unique place among medical interventions. No other medical intervention is so immediately contingent upon therapeutic material being provided by a patient/member of the public, rather than by a pharmaceutical or medical device supplier. Transplantation has a quasi-miraculous quality in that the gravely sick are healed through replacement of the physical matter of their bodies. Conversely, disemboweling the dead for their organs invokes nightmare scenarios, disrupting powerful norms associated with dying and death. The language of the gift is widely employed to manage the public imaginary and navigate these competing visions, between repugnance at desecrating the dead and the need for public altruism in donating organs. Members of the public are encouraged to “give the gift of life” (DonateLife 2021) by ensuring that relevant family or friends are aware of their wish to donate.

Alongside the rhetoric of the gift of organs lies a discourse about sacrifice, which allays public unease and fosters acceptance (Mongoven 2003). Deceased organ donation – the gift of life out of death – mirrors archetypes in which sacrifice is both a valuable gift and a force to counter evil. On this account the organ is sacrificed, motivated by the desire to benefit others while the ritualized surgical removal mitigates grief at the lost life of the donor.

However, this mythology of sacrifice is, according to Alice Mongoven’s feminist analysis, deeply problematic for a number of reasons (2003b). First, there is a bias at play in the framing of the lives at stake in donation and transplantation. Lives lost on the waiting list are configured as especially tragic or unacceptable. The deaths of donors, who have often lost their lives prematurely, are also acknowledged to be tragic. However, those deaths are not seen as avoidable in way that lost waiting list lives are seen as avoidable if only donors (or their families) make the sacrifice and gift their organs. This framing is problematic given the social factors at play in donors’ causes of death; at least some of those deaths are also potentially avoidable and so *prima facie*, equally tragic or unacceptable. It is not clear why organ failure should demand greater moral consideration than other conditions of premature death, which might also be avoided given appropriate social or medical interventions.

Second, calls for increased rates of deceased donation normalize expectations about sacrifice, so that those who do not donate can be characterized as selfish or uncaring. The focus on saving other lives may take little account of the particularities of the death of each potential donor, and the factors that might be morally relevant in a family’s decision about donation. While the language around organ donation ostensibly focuses on supporting families to make their own choice, the

success of organ donation programs is measured in numbers of organs procured, creating implicit if not overt pressure for organ donor clinicians to secure family consent (Tarabeih and Bokek-Cohen 2019). This pressure can lead to problematic practices. For example, Israeli transplant coordinators are trained to “befriend” the grieving families of potential donors in order to understand family dynamics that can then be used to steer the family toward donation. Families’ religious commitments are manipulated by providing transplant clinicians who are ostentatiously of the same faith and who encourage donation on faith-based grounds (ibid.). The dominance of the procurement attitude may leave little space for reflection about what is best for particular families or individuals facing the death of a loved one.

In addition to these more general concerns, feminists have reason to be wary of sacrificial ideals that can be used to routinize and feminize sacrifice (Mongoven 2003). Ideals of self-sacrifice perpetuate harms to women as they attend preferentially to the needs of others (partners, children, aged parents). Such self-sacrifice becomes lauded as an end in itself while the harms may be ignored or hidden. This sacrificial metaphor rings true for at least some transplantation-related gender inequities. Given this framing, the disproportionate numbers of women who donate kidneys to their partners is consistent with entrenched expectations that women will sacrifice whatever is necessary to meet the needs of the men they care for. Spousal donations may be construed as the un-gendered acts of caring partners, but this explanation fails given the lack of sacrificial reciprocity by presumably equally caring male spouses whose female partners need a kidney.

Unlike with living donation, the deceased donation sacrifice does not fall on the donor. The donors themselves are unconscious, dying or dead; it is family or close friends who are called on to make or affirm the gift decision. Their sacrifice is not their own body part; instead families or friends forfeit the chance to bear peaceful witness to the dying of the donor, as donation disrupts this process with additional medical procedures. Within families, donation decisions rest largely with the women who are the mothers or partners of the predominantly male deceased donors (Schirmer and de Aguiar Roza 2008). Like many female sacrifices, this one is not widely acknowledged. The focus is on the potential organs and the recipients, rendering the gendered dimension of the decision making seemingly inconsequential or invisible. A hesitant mother may be seen as a barrier to organ procurement to be won over or worn down, rather than as a woman who cannot bear once more to give up what is precious to her in order to benefit others. And while care for donor families has increased, this is framed by affirmation that the family made the right decision and gratitude for the gift of organs, rather than focusing on the emotional toll exacted by the process of agreeing to organ donation.

A further consequence of sacrificial framing is that it directs attention to the organs that are donated by specific donors and the benefits to individual recipients. This framing distracts from relevant matters of justice that permeate organ donation and transplantation such as questions about transnational organ markets and the role of poverty and oppression in sustaining that market. The participation of young men in organ black markets reflects harmful gendered role stereotypes, perpetuating ideas that men are brave, strong enough to tolerate an operation, should bear financial responsibility for the wellbeing of their families and so on. In the face of relentless poverty, selling an organ may seem a reasonable choice, or the only choice, rather than a noble sacrifice.

Further, the focus on individual decisions and gifts draws attention away from the structural and gendered processes that shape the patterns of disease and death underpinning transplantation and access to transplantation. Many differences in the prevalence of diseases that lead to organ failure are described in biological terms – protective effects of estrogens, genetically mediated male susceptibility to cancer and cardiovascular disease and so forth. But equally, many of the factors contributing to organ failure are gendered, such as smoking rates, alcohol consumption or access to healthcare. Likewise, as described in the first section, access to transplantation is gendered, shaped by socio-economic and educational factors, self-esteem and self-advocacy, having a carer and so on.

It is impossible to predict what the patterns of organ supply, need and receipt would be in a world with gender equity. Maybe fewer men would get organ failure, or maybe more women would receive the organs they need or die in ways suitable to become donors. An individualistic focus on the tragedy of lives lost on the waiting list and the heroic sacrifices of donors and their families does little to address these underlying inequities. The sacrifice/gift narrative provides no impetus to change the status quo and instead puts the focus on increasing rates of donation.

Embodiment

Feminist scholarship that draws on phenomenology offers alternative approaches to analyzing established ethical challenges in donation and transplantation, such as concerns about living donors' voluntary consent. Within this scholarship, the focus is on the embodied nature of the relationship between donor and recipient and their shared lifeworld as a precondition for the possibility of donation. This approach can both ground and critique intra-familial donations.

Kristin Zeiler's (2014) ethical framework for transplantation of "giving-through-sharing" draws on the work of Merleau-Ponty. "Giving-through-sharing" refers to the basic connectedness between the self and other that configures human existence. On her account, individuals are given in the world; that is, they come into being and consciousness situated and involved in a physical and social world. They are already in relation with others in a communal world and develop as embodied selves through shared existence and co-existence, the process Zeiler calls giving-through-sharing. The notion of giving invoked here is not that of giving away (as with a gifted organ) but rather intercorporeal exchanges of habits, skills or ways of being in the world, that give new possibilities to the embodied and embedded selves involved in the exchanges.

This approach offers an alternative to the gift framing of organ donation. Rather than focusing on the voluntary act of transferring an organ from one individual to another, the focus is on the shared bodily existence common to both donor and recipient that makes the exchange possible. Shared embodiment, and sharing-through-giving structure the conditions in which transplantation can occur, and it is these features, rather than the specifics of any particular organ, which are important. The giving-through-sharing framework offers insights into concerns about intra-familial living organ donation (Zeiler 2014). Empirical research shows that donors, especially parents, describe donation as the only alternative, claiming that they have no choice but to donate (Forsberg et al. 2004). This potentially coercive feeling of having no alternative apparently contravenes the ethical requirement for voluntariness and choice in organ donation. Based on phenomenological reasoning, Zeiler concludes that the bodily sharing that occurs between parent and child is such that their whole way of being in the world and their wellbeing are entwined in ways that make donation a natural extension of their already established giving-through-sharing. On her account, reducing this complexity to a concern about voluntary choice misses the ethical point of embodiment, intersubjectivity and ways of being in the world with others.

While allaying ethical concerns about at least some parent-child donations, Zeiler's approach also offers a way of thinking about potentially problematic instances of living donation. Bodily habits and ways of being given in the world may be shaped by interactions that fall far short of parental love and which curtail embodied possibilities in ethically troubling ways. As discussed above, the majority of unpaid living-related kidney donors in Western countries are female spouses, while male partners are relatively infrequent donors. Embodiment offers an approach to thinking about the different choices of the women and men involved (or not) in these donations. The choices may reflect the affordances offered by their individual embodiments and the particular giving-through-sharing to which they have been habituated. The women donors may be habituated to "being-at-others'-disposal" through embodied expectations within their marriage and associated social roles. These spousal donors may be habituated to the needs of their partners through

a lifetime of routine interactions that limit choice without apparent coercion. This situation may make acquiescing to the implicit or explicit expectation that they will donate a kidney to their male partner seem normal and inevitable rather than coerced. Likewise, the giving-through-sharing of male spouses has been shaped by their physical and social worlds. Within those worlds, ingrained expectations about the support due from their spouse, or the perceived need to not compromise their role of financial provider by having an operation may shape their expectations about either receiving an organ or being a spousal donor. Zeiler's embodied approach helps to explain some of the gender inequities in living organ donation by showing that individuals' decisions about donation should not be seen as a simple matter of exercising their freedom, understood narrowly in terms of voluntary choice.

Care and dependency

Like feminist phenomenology, care ethics takes account of morally specific features of the relationships within which people live. Care ethics identifies the responsibilities that arise within social and familial relationships, and in particular, the gendered way those responsibilities accrue. This approach aims to provide a moral blueprint for relationships in which both the carer and the cared for acknowledge the moral (and physical and psychological) work caring entails.

Transplant recipients are very much in need of care. The surgery is major, especially for liver and heart transplantations, followed by onerous regimes of unfamiliar medications and ongoing medical surveillance. Being a transplant recipient is not something that a person can do on their own. The need for a carer creates a potential problem for equitable allocation of organs. While ethical guidelines typically state that there should be no discrimination on grounds including relationship, social or other status, there is a requirement for a reasonable likelihood that the recipient be able to adhere to the necessary post-transplant regimes, known as the social support criterion (see e.g. NHMRC 2016). This criterion acknowledges recipients' need for support to be able to comply with post-transplantation requirements. There is however little acknowledgment of the gendered nature of this support. This is troubling because, first, more men than women need transplants. To the extent that male recipients are in heterosexual partnerships, this immediately places their female partners in the caring role. Taking on this role is an extension of already gendered patterns of healthcare within relationship/families, in which women assume responsibility for family health (Drake 2018). Caring for a transplant recipient is an onerous and time-consuming responsibility. The cost of this emotional and physical work, including high stress levels and loss of income, is rarely acknowledged or factored into the economics of transplantation (Fuller 2019). The recipient of the heroic intervention is at the center of social and medical attention while the usually female carer is an oft-invisible element of the background conditions that made the transplantation possible.

The need for a carer disadvantages women in a second way. Women tend to get organ failure at older ages than men, at a time when they may have outlived a male spouse or their spouses may be frail and/or not competent to take on the carer role. Either way, if women lack the necessary supports to comply with post-transplantation regimes, they are thereby not eligible for transplantation. This makes the social support criterion inequitable for both women who must take on a spousal carer role and for women who are ineligible for transplantation because they lack a carer. Care ethics encourages attention to patterns of inequity that arise from norms about who provides and who receives care. This focus is necessary to disclose these gendered patterns of inequity that arise despite the apparently gender-neutral social support criterion.

Rather than being gender neutral, the criterion reinforces social expectations for women to provide essential care for men and advantages men in heterosexual relationships. Further, we have no information about how these issues play out among gender diverse individuals, and/or same sex

couples and families. There may be troubling intersections between gender, sexuality and relationship status that impact on transplant eligibility, about which we know little due to lack of relevant research.

Women in research

Feminists have long been concerned about the exclusion of women from research and the associated harms that accrue when data collected from men are generalized to women (see e.g. Dresser 1992). Historically women were excluded for physiological reasons, with researchers preferring allegedly stable male bodies over those with fluctuating hormonal cycles or that might be pregnant. Simultaneously and contrariwise, female difference was deemed irrelevant when it came to applying results from male-only research to women (Rogers 2004). Lack of sex and gender-specific research leads to inadequate evidence for effective medical interventions for women. There are consequent harms from poor access to effective treatment and physical, emotional, financial and social impacts when inappropriate treatments based on male physiology fail to work for women. Nonetheless, under-representation of women in research persists across many medical domains including transplantation (Laprise et al. 2019).

An associated issue relates to the inconsistent use of the terms “sex” and “gender” in transplantation research (ibid.). Disentangling the two is both challenging and contestable but there are accepted definitions for the purpose of medical research revolving around a biology-culture distinction.² However, Laprise et al. found incorrect uses of the terms, with papers using gender for research outcomes relevant to sex and vice versa, as well as frequent interchangeable use of the terms. Conflating the two in research can lead to a lack of discrimination between biological features such as effects of sex hormones or immune responses, and socio-cultural factors such as compliance with treatment or gender bias. Lack of adequate specification can lead to a “gender-fatalism” in which stereotypical but modifiable social norms are taken to be sex-based differences written in the chromosomes, such that associated differential treatment is seen as a matter of nature rather than justice. It is possible that some of the unequal access to kidney and liver transplantation experienced by women is due to clinicians conflating gender-related outcomes with sex-based differences, leading to women being deemed less suitable recipients than men with equivalent need.

Untangling social from biological impacts on donation and transplantation is critical to address some of the inequities identified in section 1, such as the role played by physician discrimination in the lower liver transplantation rates of women compared with men. To do this requires clarity on the part of researchers as to whether they are investigating sex- or gender-related issues and using the relevant descriptors accurately, but as Laprise et al. (2019) note, there are no standardized tools for measuring gender-related dimensions in the context of donation and transplantation. We need nuanced investigation to disentangle the effects of sex and gender on, for example, renal transplant outcomes in women where biological factors including immune responses contribute to worse outcomes but gendered factors, such as adherence to immune suppression contribute to better outcomes (ibid.). All relevant research should include women and men in adequate numbers for subgroup analysis (ibid.). However, equity in transplant research requires more than equal numbers of female and male participants (Rogers 2004). Where there are current inequities, such as in the listing of women for heart transplants, or the failure to list heavier women for kidney transplants, targeted research is required to develop effective ways of remedying these inequities. Research is likewise required to investigate the impact of characteristics such as racialized group, age, gender diversity and socio-economic status as these intersect with gender in donation and transplantation. Of note, many of the references on sex, gender and transplantation cited in the first section have female authors, reflecting the need for equal participation of women as researchers and

research leaders and inclusion of women's voices in the development of transplantation research agendas (see e.g. Puoti et al. 2016; Laprise et al. 2019; Melk et al. 2019).

This section examined ways in which feminist analyses can inform and further investigate sex and gender inequities in organ donation and transplantation. In the conclusion, I indicate how tools from feminist bioethics can play a broader role in donation and transplantation ethics, beyond gender equity.

Conclusion

Despite my focus on gender inequities, there are other worrying ethical considerations raised by organ donation and transplantation. These include human rights abuses associated with organ trafficking, vulnerability (to exploitation, harms, discrimination), transplantation exceptionalism, donation associated with assisted dying, definitions of death, neglect of preventative strategies, the impact of failed organ donation on families and more. I cannot do justice to these topics here, but instead will gesture toward current and potential contributions from feminist bioethics.

First, my discussion of embodiment above was limited to implications for gender equity, but the phenomenological approach has more to offer. For example, Margrit Shildrick (2008) challenges the mechanical model of replacement parts that dominates transplantation rhetoric by investigating how changes to the body change the self. On her account, the donated organ is essential to the wellbeing of the recipient but is tolerated only through taking immunosuppressant drugs, creating an uneasy nexus of self and other experienced as a change in identity. Shildrick uses conceptual resources from phenomenology and focuses on the lived experiences of individuals, but the identity implications of living donation and transplantation also lend themselves to feminist narrative approaches, both to identity itself and/or as a method of analysis (Lindemann Nelson 1997).

Feminist narrative approaches are well suited to identifying the impact of organ donation practices, such as impacts of living donation on family members (Lin et al. 2021) or the harms of failed donation (Taylor et al. 2018). Neither of these papers are explicitly feminist but their attention to the specifics of individual experience speak to the importance of understanding the impacts of organ donation beyond the current metrics of families recruited or organs procured. Feminist empirical research offers fertile ground for interrogation of the power relations at play, notions of familial duties, the phenomenology of grief and potential new measures of the harms and benefits of organ donation and transplantation.

Likewise, vulnerability theory offers a potentially valuable lens for further interrogation of some of these ethical issues. Feminist accounts of vulnerability (Rogers, Mackenzie and Dodds 2012) highlight both the shared universal nature of vulnerability and the importance of distinguishing and ethically evaluating different sources of vulnerability. A vulnerability approach could illuminate how risks of organ failure accrue unequally across populations and between individuals, or offer a critique of crowd-funding approaches to transplantation (see e.g. Pol, Snyder and Anthony 2019) that impose pathogenic vulnerability on those who lack technical means or photogenic faces. The links between justice and vulnerability offer new ways of conceptualizing the wrongs of organ trafficking while feminist attention to structural injustices can help to unpick the links between disadvantage and organ failure.

These are just some of the many ways in which feminist bioethics can contribute to the ethics of organ donation and transplantation. What I hope to have shown is that gender and sex are central to transplantation and have far reaching effects, some of which are inequitable. Feminist bioethics has made significant contributions to analyzing these issues, offering fresh insights and conceptual tools that are well suited to a broad analysis of the ethics of organ donation and transplantation.

Related topics

Care and carers (Eckenwiler: Chapter 6); vulnerability (Luna: Chapter 7); embodiment (Zeiler: Chapter 9); narrative and identity (Walker: Chapter 10); gender (Hendl and Browne: Chapter 11); women in research (Ballantyne: Chapter 18); gender, science and technology (Ankeny: Chapter 19); health and disease (Bluhm: Chapter 23); care ethics (Dodds: Chapter 26).

Notes

- 1 Throughout I use “differences” or “inequalities” to refer to transplant-related variations between men and women, and “inequities” to refer to that subset of differences that are unjust because they reflect discrimination or other unfair treatment (Arcaya, Arcaya and Subramanian 2015).
- 2 See e.g. Wainer et al.: “Sex refers to the biological and physiological characteristics that define humans (and other species) as male, female or intersex, based on chromosomal complement. Gender references roles, behavior and activities that a given society, at a given time, considers appropriate for men, women and gender diverse persons” (2020: 57).

Further reading

- Lin, Y.-P., Chen, J., Lee, W.-C. et al. (2021) “Understanding Family Dynamics in Adult-To-Adult Living Donor Liver Transplantation Decision-Making in Taiwan: Motivation, Communication, and Ambivalence,” *American Journal of Transplantation* 21(3): 1068–1079. (An ethnographic study exploring pressures to donate within families.)
- Lundin, S. (2015) *Organs for Sale: An Ethnographic Examination of the International Organ Trade*, Basingstoke: Palgrave Macmillan. (A detailed investigation mapping pathways to and experiences of black market organ sales.)
- Melk, A., Babitsch, B., Borchert-Mörlins, B. et al. (2019) “Equally Interchangeable? How Sex and Gender Affect Transplantation,” *Transplantation* 103(6): 1094–1110. (An accessible account of sex and gender impacts on transplantation.)
- Mongoven, A. (2003) “Sharing our Body and Blood: Organ Donation and Feminist Critiques of Sacrifice,” *Journal of Medicine and Philosophy* 28(1): 89–114. (A detailed analysis and critique of the gift/sacrifice metaphor in organ donation.)
- Zeiler, K. (2014) “A Phenomenological Approach to the Ethics of Transplantation Medicine: Sociality and Sharing When Living-with and Dying-with Others,” *Theoretical Medicine and Bioethics* 35(5): 369–388. (A detailed analysis of the phenomenology of organ donation.)

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