14. Problematizing the Rhetoric of Gift-Giving in Transplantation Narratives

Epistemic Authorities

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1. Introduction

Social scientists have long argued that reciprocity is a basic principle of social life and a social norm of gift-giving (Berking 1999; Gouldner 1996; Simmel 1996). According to Komter (2005), however, the reciprocity rule does not directly apply to substances of human origin that are deemed bodily gifts, such as blood or organs. This is not only due to the treatment of blood and organs as part of a global economy of tissue exchange in which human body parts and products are transformed into commodities with biovalue (Waldby/Mitchell 2006), but because the donation of bodily gifts is typically assumed to be altruistic; freely given, one-way, and disinterested. Komter's sociological observation does not simply describe current institutional and organisational arrangements, it is also a value promoted by stakeholders, professional groups, and policy makers. That is, the prevailing moral guideline in global north jurisdictions is that bodily organs should be treated as gifts and only ever voluntarily donated as an act of altruism (Berglund/Lundin 2012). In this rendering, altruistic donative acts should be intentional, voluntary, and seek to enhance the welfare of others without external influence, expectations of reciprocation or commercialization (Shaw 2019).

There are multiple ways to conceptualize gifts and gift-exchange in social life. While many scholars emphasize the polysemic and paradoxical nature of the gift as unilateral and reciprocal, self-interested and altruistic, voluntary and normative (e.g. Berking 1999; Godbout/Caillé 2000; Godelier 2002; Mauss 1990; Osteen 2002; Schrift 1997), the complexities of this understanding tend to be subsumed by the language used in health care information manuals and in biomedical policy guidelines and protocol. As Tutton (2002) points out, the gift is typically conceptualized by ethics committees, medical councils, and research institutes interested in fostering the donation of body parts and products as a one-way transaction (e.g. *UK Human Tissue Authority* guidelines). Drawing on the legacy of Titmuss' (1997) comparative research on commercial and voluntary blood donation systems in the UK and US in the late 1960s, the language that is used in these contexts to talk about donation is couched in terms of the 'gift relationship'. Typically, the gift relationship, which is underpinned by the notion of reciprocity, is conflated with altruism and the pure gift as unconditional.

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The example Tutton gives that exemplifies this kind of thinking comes from the Medical Research Council (MRC) in the UK, which states that treating bodily donations as gifts is "preferable from a moral and ethical point of view, as it promotes the 'gift relationship' between participants and researchers, and underlines the altruistic motivation for participation in research" (in Tutton 2002: 523).

However, as international researchers have shown (Fox/Swazey 1992; Sharp 2007; Shaw et al. 2012; Shaw/Webb 2015; Siminoff/Chillag 1999), the multiple meanings of the term gift and its conflation with altruism can lead to problems when people have different ideas about what a gift is and how to give and receive it. For some people who donate and receive substances of human origin, the transfer of bodily material is not an altruistic act over which control is unilaterally relinquished or surrendered (Shaw 2008). Rather, bodily gifts establish on-going reciprocity relations between donors and recipients and failure to return a gift, or to show gratitude for a gift, symbolizes a refusal to cement the social and moral bond. Treating bodily donations as an altruistic act can therefore fail to account for the complex entanglement of psychosocial and intercorporeal processes occurring between participants involved in organ donation and transplantation (Shildrick 2012).

In keeping with legislation and policy elsewhere in the global north, the language of the gift is used in New Zealand to promote organ donation as an altruistic act. In this chapter, I examine the salience of this terminology to describe and understand the experiences of organ donors, donor families, and transplant recipients. To do so, I draw on the concept of epistemic injustice as described by the philosopher Miranda Fricker (2007, 2008) as a dysfunction in our knowledge practices. The rationale for applying Fricker's approach to this discussion is to show why the inclusion of perspectives from the standpoint of organ donors, donor families, and transplant recipients is ethically needed and justified, and to emphasize the importance of qualitative social science research in bringing these views to bear on our collective understanding of organ donation and transplantation processes.

2. Theoretical Framework: Epistemic Injustice in Organ Donation

Epistemic injustice occurs when "particular powerful or dominant groups, can limit or occlude knowledge production and transmission by powerless or marginalized groups" (Mason 2011: 294), resulting in a partial knowledge base. According to Fricker epistemic injustice can occur in two ways. Hermeneutic injustices occur when a gap in collective understanding delimits a group or individual's ability to make sense of or articulate their experiences to others (or oneself). Testimonial injustices occur when the hearer, usually a member of a dominant group, assigns "a prejudicially deflated degree of credibility" (Fricker 2008: 69) to a speaker's words or utterance, thereby discounting or ignoring the speaker's perspective based on preconceptions of their social identity. The harms that result from these forms of unknowing prevent a speaker from being heard or silence a certain group or individual unfairly through processes of testimonial quieting and testimonial smothering (Dotson 2011), making it difficult for such groups and individuals to reclaim or assert their epistemic agency.

Against the theoretical background of Fricker's and Dotson's work, I will draw on qualitative data from a series of linked empirical studies conducted in New Zealand

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on organ donation and transplantation, which I will call the New Zealand study for the purposes of the chapter. I suggest that the dominant health care discourse in this domain, including the discouragement of communication and contact between organ donor and transplant recipient families and communities, can result in forms of epistemic injustice as identified by Dotson. Testimonial quieting occurs when a patient's knowledge is devalued because they are perceived as lacking credibility, and testimonial smothering is the failure to acknowledge the content value of a patient's viewpoint, because it is at odds with so-called expert-knowledge, thereby leading to self-silencing and communicative editing to conform to dominant discourses or scripts. Adopting Dotson's reading of epistemic injustice, the New Zealand study findings indicate that framing organ donation as an altruistic gift "marginalizes the voices of those who are anything less than straightforwardly grateful for their transplant" (O'Brien 2017: 294) and obscures the multi-faceted nature of indebtedness and gratitude to the donor. I suggest that privileging dominant ideals around anonymity protocol prevent some donors and transplant recipients from voicing alternatives or questioning the values embedded in this discourse, such as diverse ways of thinking about the interplay of embodiment, bodily integrity, and identity; thereby diminishing the total knowledge base and service delivery in this context. This may explain why some donor families and transplant recipients experience difficulties and resistance to accepting status quo attitudes around gratitude and reciprocity when giving and receiving organs.

3. Cultural Background: Organ Donation in New Zealand

Although the past decade has seen an increase in organ donations globally, low donation rates in many high-income countries are rendering transplant waitlists lengthy and unpromising (Larijani/ Zahedi 2007). Many countries with transplant programs have endeavored to boost the rate of altruistic donation, yet progress is often slow moving, and, in some countries, the rates of donation have plateaued (Matas/Delmonico 2012). When compared internationally, New Zealand's donation rates remain among some of the lowest across high-income countries at 15.2 deceased donors per million population (ANZDATA 2018).

Where deceased donation is concerned, unmediated contact between organ donors, donor families, and recipients of organs and tissues is institutionally discouraged, as is unmediated contact between living non-directed donors and transplant recipients. Various reasons are given not to allow meetings between donors and recipients, including support for the concept of organ donation as an unconditional gift, as well as protecting the anonymity of the donor (Ministry of Health 2004). The Organ Donation New Zealand (ODNZ) website states that donor families are given brief details about the recipients of their family member's organs and tissues, should they wish to receive this information.[1] Moreover, letters can be forwarded by transplant coordinators between donor and recipient families with their consent.

Meetings between donor and recipient families can occur, but they are infrequent due to the careful mediation of social distance between respective individuals and families by health professionals, psychologists and counsellors. One possibility for connec-

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[1] https://www.donor.co.nz/facts-and-myths/faqs/ (accessed February 9, 2020).

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tion between donors and recipients occurs in major New Zealand cities in cathedrals where Thanksgiving Services are held for donor families and organ recipients. At these services, transplant recipients are invited to light a candle as a symbol of gratitude to those who have given them renewed life and members of donor families are invited to receive a variety of Camellia plant called 'Donation' in recognition of their 'gift'. The service is followed by Lunch at which it is possible for donor families and recipients to serendipitously meet, thereby collapsing the social distance required of anonymous donation to a stranger. Despite media anecdotes suggesting otherwise, professionals working in the donation area maintain that matching donors with recipients at these services is not common practice. It is nonetheless difficult to say categorically that people do not try to meet up at Thanksgiving Services and that the purpose of the ceremony, for people to recognize and share a view of the ceremonial significance of the ritual as a social good is paramount, as the ends of individuals attending these such services may be very different. Some people are keen to objectify the symbolic act of donation via more tangible social relationships and believe that prohibiting meetings is "the ultimate in paternalism" (Ministry of Health 2004: 95), preventing closure for families who may then go to lengths to circumvent so-called anonymity protocol.

4. Methods

In this chapter I provide a general overview from previously published work of the perspectives of Transplantation specialists and Intensive Care specialists (Intensivists), deceased donor family members, non-directed living kidney donors, and organ transplant (heart, kidney, lung) recipients from a series of linked qualitative studies based on face-to-face interviews and fieldwork conducted in New Zealand between 2007 and 2013.[2] This includes data from studies with 15 Intensivists and Donor and Recipient Coordinators, 11 Transplantation specialists, nine members of deceased donor families, six non-directed live kidney donors, 27 transplant recipients, and 15 Māori donors, recipients and whānau (Māori are indigenous inhabitants of New Zealand; whānau is a term meaning extended family). Data from the health care professionals is included in this discussion because these practitioners are on the front-line of providing services and advice to those seeking organ transplantation and have an overview of issues that affect access and experiences supporting a range of different patients from various cultural backgrounds.

The Intensivists and Transplantation professionals, recruited by convenience and snowball sampling, were interviewed at their place of work. Advertisements in national media and websites were used to recruit organ donor family members and transplant recipients, who were interviewed in their homes or at a location convenient to participants. All participants were self-selected and written informed consent was obtained for interviews. The interviews took between 60 and 150 minutes. All the interviews were transcribed verbatim, and then sent to participants for review and editing upon request. The participants were asked open-ended questions structured around guid-

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[2] The studies all received research ethics clearance (Victoria University of Wellington 2-2007-SACS; Multi-Region Ethics Committee MEC/08/03/027; Victoria University of Wellington HEC 16628/4/06/09; Multi-Region Ethics Committee MEC/11/EXP/089).

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ing interview themes relevant to each participant group. The natural pattern for organ recipients was to begin with explanations of illness onset and then discuss physical symptoms, mishaps and problems before broaching explicitly moral questions. Donor family members also began by discussing illness onset associated with their loved one, and the living non-directed donors began their conversation by recalling the event or occasion that gave rise to their decision to donate a kidney. Pseudonyms have been used to protect confidentiality.

The interview transcripts were read and re-read, and the data were coded manually and checked by the author before being analyzed thematically (Braun/Clarke 2006). The themes were then linked back to phenomenological theory about embodiment and perceptions of moral identity in relation to organ transfer (Haddow 2005, Shildrick 2008). Collectively, the data sets document how the respective roles, beliefs, and understandings of different groups of interviewees toward human embodiment, identity, and wellbeing shape and frame their attitudes and moral experience of organ donation and transplantation.

5. Interpreting Results of the New Zealand Study

5.1 The Language of Gratitude

Although deceased donation has increased dramatically over the last four to five years in New Zealand, numbers remain comparatively low, despite concerted education programs and media publicity to increase awareness of donation rates. Such programs frame organ donation as unambiguously life-giving, emphasizing themes in the personal stories of transplant recipients around living one's life well to honor the donor and their gift. For example, ODNZ, which is currently the national coordinating agency for deceased donation in New Zealand, uses the tag line 'Organ Donation – the gift of life' to accompany its logo on the official website. In November 2019, a word search for the term 'gift' on the website produced 136 hits, mainly in reference to stories about people's transplantation journeys. Likewise, the opening statement of the Increasing Deceased Organ Donation and Transplantation national strategy summary reads: 'Organ donation is a very special gift'.[3]

Because organ donation is supposed to be a selfless act of giving and generosity that grants new life to the recipient, many of its rituals promote and memorialize its life-giving aspects. In the New Zealand study, for example, several transplant recipients talked about their 'second birthdays'. Helen, a mother of a transplant recipient, whose husband was also a deceased donor, spoke explicitly about the ritual of the 'second birthday', stating: "In our family we still celebrate *[son's name]* transplant birthday." Such comments follow a sanctioned script, heavily reliant on interlocutors to master certain phrases and expressions to describe their experiences. The following statement is typical: "I mean it really is like a rebirth. You just feel a sense of gratitude that you can never possibly feel… I mean, um, having a second chance of life is better than winning, being a billionaire."

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[3] https://www.health.govt.nz/publication/increasing-deceased-organ-donation-and-transplantation-national-strategy (accessed February 9, 2020).

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The language of gratitude embedded in this discourse links the moral agency of the patient to expectations around self-care, including 'compliance' or 'adherence' to healthy diet and drug-taking regimens, as well as regular exercise. For those on kidney dialysis waiting for transplantation, and for transplant recipients who are required to take a cocktail of drugs each day at specified intervals their own and others' worthiness to receive an organ is a key concern. The following comment by a transplantation specialist emphasizes the magnitude of the gift that is conveyed to organ recipients. In the specialist's view, this requires acceptance of the sick role; that is, valuing the donated organ means seeking professional help, taking medication, getting better, and moving on with their life.

> It is vital that the recipient of a transplanted organ takes ownership, if you like, of that organ, and I think it's very appropriate that they are mindful that this is given from a family at a very difficult time. [...] Not that you'd want them to wander around and start saying 'thank you, thank you, thank you', but you want them to take their tablets, you want them to keep fit and you want them to attend appointments; that's all we ask.

Related to the specialist's characterization of the transplant recipient as a 'good patient' who takes personal responsibility for managing their health by avoiding risky, deviant, or resistant behaviors around dialysis, diet, and self-care, transplant recipients also speak about coming up against other interpersonal and organizational impediments that constrain their ability to express moral agency freely.

One concern for recipients in their efforts to connect with donors and donor families is related to the ability to convey gratitude and reciprocity. Some transplant recipients experience so much guilt associated with reciprocation that it produces anxiety around the process involved in thanking donor families. Consequently, transplant recipients are mindful of respecting the privacy of donor families and their rights to confidentiality, taking special care to avoid approaching them at public Thanksgiving services (held annually at city cathedrals) without warrant. For instance, Daphne, a kidney recipient who had two failed transplants, said she did the 'right thing' by not writing to her donor family, as she did not want them to think their donative act was in vain.

However, for many transplant recipients whose operations are successful, the desire to say thank you is a paramount concern. For some, making direct contact with non-related donors and donor families is an expressed desire, despite sometimes feeling overwhelmed by the prospect. Eryx, one kidney recipient, was actively interested in meeting his donor family until he heard the mother of a deceased donor unexpectedly share her grief over her daughter's death at a Thanksgiving service. The mother's distress at the distribution and re-location of her daughter's seven organs in strangers' bodies across Australia and New Zealand (there is a reciprocal organ sharing arrangement between these countries) was too much for this recipient to bear.

5.2 The Anonymity Imperative

To preserve the privacy of those involved from making direct contact, a so-called anonymity imperative protects donors and recipients in deceased organ donation and is carefully managed by those who work in this domain. There are various reasons given

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for ensuring anonymity between organ donor families, and transplant recipients and their families. The current practice in New Zealand is to support the sharing of general information about transplant outcomes, but withhold personal information about donors to transplant recipients and discourage meetings. Recipients do not know the name of their donor and they are not given contact details about their family. Many recipients know only their donor's age and occasionally their gender, although in one New Zealand District Health Board catchment the practice was strictly not to give out this information.

Sharp identifies the rationale health professionals in the USA have used for ensuring the anonymity mandate (which is similar elsewhere): to respect donors and donor families' privacy, free from intrusion in the grieving process; to prevent recipients identifying psychologically with donors; and to protect recipients from overwhelming feelings of guilt because "someone had to die so that they could live" (2006: 106). In Sharp's view, one of the problems associated with not naming donors to recipients is that the practice consigns deceased donors to a nameless and "generic category of dead" people (Sharp 2007: 35). Moreover, the inability of recipients to name donors obscures the identities of organ donors and not only silences recipients but also donor families. Anonymity protocol therefore denies people "the opportunity to tell their stories and speak of personal pain and loss" (ibid.). Data from the New Zealand study confirm Sharp's observation about the silent narrative of pain, loss, and guilt, especially in conjunction with attempts to establish moral connection with donors and donor families. A key question is how donors and recipients can give voice to these concerns within the constraints and parameters of public discourse around organ transfer.

The language available to participants to articulate themselves plays a key role in determining what one can say about the experience of organ donation and transplantation, whether one's testimony is likely to be heard, and how it is responded to by health care professionals and stakeholders. Recipients' stories told in the public arena in New Zealand, such as the ODNZ website, and at Thanksgiving services at national cathedrals designed to thank donors and their families, contain certain taboos in the storytelling (e.g. donor family members are not supposed to publicly express distress about their loved ones' organs being 'scattered' around the country). While the language used communicates shared feeling it also delimits what can be said and felt. For Siminoff and Chillag (1999), gift-of-life rhetoric is a key culprit, constantly operating as form of 'social control' to remind recipients to comply with care regimens as gratitude for their second lease of life. In short, the emphasis on life and repeated references to rebirth, renewal and salvation denies painful "emotional outbursts, *[and]* graphic accounts of suffering or death" (Sharp 2006: 109–110).

The stories that people are permitted to publicly impart about their experiences of organ donation and transplantation require them to manage their emotions by following scripts or adopting a prescribed narrative form. This relates specifically to gift rhetoric; terminology some organ recipients are more inclined to use than donors and members of donor families. Although most participants in the New Zealand study did not interpret the gift-of-life anthropologically, many transplant recipients nonetheless understand gifts as signifying relationships based on giving, receiving *and* reciprocating (Shaw/Webb 2015). This kind of gift relationship is cut short when organ transfer policies and practices conceptualise gifts as one-way transactions, promoting generalised but non-specific forms of reciprocity. So, although donor and recipient anonym-

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ity operate to ensure the unidirectional gift as unconditional and disinterested, some transplant recipients never feel free of their moral responsibilities toward donors, donor families, and the transplant community.

5.3 Reciprocity: Saying Thank You

In New Zealand, transplant recipients are permitted to write thank you letters to their donors or to donor families, which are then passed through recipient and donor coordinators to ensure anonymity and privacy between the two parties. This is clearly important for both organ and tissue recipients and donor family members. Indeed, it bothers recipients' moral memory, as Simmel (1996) put it, when they are unable to say thank you to their donor families. Many recipients talk about the difficulties of writing the thank you letter given the magnanimity of organ donation, especially when it is couched as a gift. For example, Anteia, a lung recipient commented that:

> It took me a year to write that letter. I started after about six months to write it and I had it on my PC, and I'd start to look at it, and I'd sit there and cry and make a few adjustments to it. And then I'd think no, that's not right either. What do you say to somebody who saved your life basically? And they are going through their grieving process because their family member died. So, it was a really, really, hard letter to write. And it must have been over a year before I thought; well I can't say any more than I did.

While letter writing provides an opportunity for recipients to say thank you, letters do not always ease the burden of guilt for many recipients who are troubled for years after their transplantation operation about how to say thanks. O'Brien (2017), drawing on research conducted in Australia, suggests that heart recipients feel this more acutely than do liver and kidney recipients, due to the higher social value accorded to the heart than to other organs. Andreus, a male heart recipient from the New Zealand study, emphasizes the magnitude of his 'gifted' organ in the following quotation:

> Obviously, I'm thankful and I'm glad that that's what they considered *[organ donation]*. But I tried to write some letters… and I just couldn't, it was just garbage. Emotionally it wasn't garbage, it was just straight from my heart, but you just couldn't read it. You can't tell someone something like that after they'd given you; you know given away I guess a part of their self or their family… I mean you need to be articulate and considerate and thoughtful, and it's just, I couldn't do that. I tried and tried and tried, it's, and I, and I remember *[name of Transplant coordinator]* saying, 'Just write something to the point, you know, just be simple', but… I think I probably should just do that, but it just doesn't seem like reciprocity, it doesn't seem like giving anything significant.

Likewise, Elissa, a female heart recipient who never wrote to her donor family, said:

> I have absolutely no idea of what I would say. I just couldn't bring myself to… I tried to write a few things and when my words were entirely, entirely inadequate I gave up. Now I've regretted that a few times, because I thought that the donor families probably, I don't know any donor families, so I can't comment for certain, but I believe that the

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> donor families actually like getting that communication. I think they like that, by and large.

Interviews with eight of the donor family members in the New Zealand study indicated that this is generally the case. Several appreciated the letters and cards they received and found them 'inspiring'. All stated they felt good knowing other people benefitted by their decision. However, one donor family member (Dymas) remarked that he did not know he could receive communication, and Castalia, another donor family member, remarked that the letter she received gave her no solace whatsoever. For Castalia, the donative act was simply 'intellectual', and she felt no connection to the recipient. Alluding to the sacrificial element in organ donation that is often hidden by an emphasis on giving the gift-of-life, Castalia conveyed a deep sense of ambivalence about organ donation as a social good and her failure to protect the body of her mother, whose organs her family donated. The vulnerability of the donor is also conveyed in the following account by a prospective interviewee in the New Zealand study. After some deliberation, this person eventually decided not to be involved in the project after initially consenting to an interview. This person, who offered to talk about donating her son's body tissues after his suicide declined to participate saying, "my rational mind says 'yes' *[to an interview]*, but my emotional mind is cautious." Because she was engaged in her own research project at the same time the study was being conducted the woman conjectured that she would be too "emotionally depleted" to participate.

Given the global shortage of donor organs to save human life it is not surprising that discussion of sacrifice to which these donor family members allude is missing from the terms of reference in public debate. In short, the language of sacrifice speaks plainly of death and the literal disassembling of human bodily integrity. Reflecting on the difficult decision-making involved in deceased donation, several Intensivists spoke of it as a 'trade off' between viewing organ donation as altruistic and sacrificial. Their view was that organ donation is a painful event for donor families and not to be treated lightly (Shaw 2010). For this reason, Sque et al. (2007) maintain that understanding the sacrifices involved in organ donation may go some way to explain the reticence of some donor families to donate – especially in cases where these sacrifices are inadequately memorialized. While gift terminology partly captures the motivations and emotions of some participants involved in donation and transplantation processes, Sque et al. (2007) suggest that the dominant visibility of this theme in fact effaces a "darker side" to donative practices, articulated in terms of sacrifice.

5.4 Intercorporeality and Narratives of Solidarity

In contrast to narratives of sacrifice, grief, and loss, are accounts that foreground the intense identification some recipients feel for their donor and the importance they attach to being able to establish meaningful ties with donor families. From a phenomenological perspective, the notion of intercorporeality encapsulates the perception of ideas and feelings about donor-recipient connection – or the lack thereof – in a bodily, subjective, and social sense.

For some people, the incorporation of body parts is thought to reconstitute embodied identity in moral and spiritual ways (McKenny 1999; Sanner 2006), in that incorporating the body parts and tissues of others has implications for individual and social

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identity, culturally and subjectively. Because phenomenology holds that the body is inextricably interwoven with the self, relocating a donated organ into the body of a transplant recipient has the potential to produce anxiety for those who see the procedure as breaching norms about bodily integrity. If the organ is not only thought of as a spare part, but also has magical qualities, then the transplant recipient must integrate the new organ by becoming part of another individual.

As well as producing identifications at the level of recipients' embodied identity, the literal intercorporeality of organ transfer also produces dis-identifications, thus complicating the experience of tissue transfer for donors and recipients who regard body fragments as alienable. As transplantation research shows (Haddow 2005; Shildrick 2008), if donor families and transplant recipients think of the body as some 'thing' we 'have' and thus detachable from subjective identity after physical death then the problem of anonymity that this chapter raises may not be perceived as an issue. On the other hand, those who view the body as co-existent with personhood, and as something we 'are', may construe tissue exchange as intersubjective and corporeal, and interpret body part incorporation as permissible or impermissible for that reason.

For these individuals, organ donation is not viewed through the lens of pure altruism but as a gift relationship, bringing different groups of people together who would not otherwise be connected but for biomedical and technological innovation. For instance, several of the New Zealand study interviewees considered the donated organ alienable in terms of use but not in terms of ultimate possession, and created inexplicable kinship ties between the donor, the donor family, and the recipient that had cultural and social implications.

Some transplant recipients, for instance, did not regard the organ as property to be alienated from one body and relocated in another; rather, they treated the organ as would a custodian, with the view that it may be eventually returned (Shaw/Webb 2015). For several Māori research participants in the study, the origin of the gifted organ and the identity of the giver do not dissipate or erode when body parts or organs are exchanged, upon death, or when a body is buried (Webb/Shaw 2011). In Māori philosophy, body parts which live on outside the body can tamper with the ancestral line, if people have not followed the correct protocol or safeguards designed to recognize customary rules and observances. Knowing where donated organs come from and being able to return them, in the appropriate way, is thus important (Te Puni Kokiri 1999). In fact, for Māori who subscribe to a traditional cultural and spiritual worldview, living donation may be more acceptable under some circumstances than deceased donation. This perspective may reflect a hermeneutic gap for some health care professionals, especially as it is not aligned with the 'dead donor rule' of transplantation medicine and puts the living donor at risk.

While some study participants envisaged the idea of an imagined community of donors, recipients, and their families, for other participants in the study organ transplantation caused ontological anxiety. They reflected on incorporating the personal and embodied qualities of the donor through the organ transfer process and said they needed to know more about their donor to allay anxieties about the strangeness of the organ transfer experience. A woman lung recipient initially felt uncomfortable about the lung she received because she thought it was from a man. She subsequently "found out my donor was female, a lady in her forties, and I immediately felt happier."

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Unlike recipients who had an intercorporeal view of embodiment through organ transfer, some interviewees thought the notion that one takes on personal attributes and qualities of the donor through tissue exchange was far-fetched. In contrast to what other researchers say about the symbolic weight of the heart for transplant recipients (cf. Svenaeus 2012), Elissa said the idea of psychic and social communion with her donor was "irrelevant". She remarked, "It's only about how the heart feels in a physical sense, like how it's functioning, that's all that matters." Likewise, Maia, a lung recipient who had received a transplanted lung did not invest her organs with personhood, stating that her old lung "was a hunk of meat" and that her body was simply a vessel for her soul or spirit.

It is significant, given these quotations, that researchers point to evidence indicating that people who view donated organs as spare parts do better post-transplant clinically and psychologically (at least initially) in terms of integrating the organ as part of their new sense of self (Siminoff/Chillag 1999; Shildrick 2008). These recipients are grateful, but they do not construct fantasies of establishing relationships with their donor and donor families. Their perspectives, furthermore, tend to be accepted by health care professionals as compatible with altruism as a one-way transaction and organ donation as a gift-of-life.

6. Testimonial Quieting and Smothering in the Field of Organ Donation

Several scholars have argued that ill persons are vulnerable to epistemic injustice because they may be regarded by health care practitioners as cognitively unreliable, emotionally compromised, and existentially unstable in ways that render their own testimonies of their health and illness experiences suspect (Carel 2016; Schicktanz 2015). This situation arises because practitioners and health care services privilege certain forms of evidence and ways of knowing and sharing knowledge that patients are said to lack. For patients to be heard, Carel maintains that their testimonies need to be expressed in the "accepted language of medical discourse to be assigned epistemic authority" (2016: 3).

In tissue economies involving organ donation, educational and recruitment organizations incorporate altruistic ideals into promotional discourse to encourage donation awareness and engagement. Although the values of organ donors and tissue providers are not necessarily aligned with the interests of educational and recruitment organizations, individuals are obliged to make sense of their actions in institutional contexts by strategically drawing on the resources that these institutions and organizations provide. These institutionally constructed discourses become cultural scripts that provide people with tools to communicate linguistic competencies, and, as justifications for their actions, legitimize entitlement to inclusion as moral subjects and members of certain groups. Accessing and using a recognizable vocabulary is thus an important step in determining the credibility of transplant recipients, donor families, and donors (Shaw 2019).

While learning new terms can be hermeneutically empowering it can also result in ways of talking that enact testimonial smothering and silencing. For some donors, donor families, and transplant recipients, for example, the accepted vocabulary of gift terminology is regarded as hackneyed, trivial, and lacking in communicative nuance.

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Individuals who are critical of gift terminology report that it sentimentalizes what could be emotionally and psychologically easier to deal with if the language used was more neutral. Several interviewees in the New Zealand study for instance regarded the descriptors 'health intervention' and 'donation' as preferable, although they felt that the appropriateness of these terms depends very much on what is being donated, to whom, and for what purposes. These participants contended that talking about organ donation as a gift of life overshadows how ill people with organ failure become, and conceals the difficulties of accommodating an alien body part and living day-to-day with the impact of immunosuppressant medication (Shildrick 2012, Sothern/Dickinson 2011). Aside from the experience of post-transplant health as a state of 'persistent liminality' (Crowley-Matoka 2005), permanently vacillating 'betwixt and between' life as sick and healthy, gift language fails to convey the impossibility of reciprocation, especially in the case of anonymous donation (Fox/Swazey 2009). It thus orchestrates what Hochschild has referred to as feeling rules around obligations to give and receive; scripting what is possible for recipients to say by framing accounts of the transplantation experiences in a language of indebtedness (Shaw 2015).

Like transplant recipients who self-silence their experience of organ transplantation as a state of 'persistent liminality' in order to become 'good patients' and present a positive public face, organ donors also self-edit to convince health care professionals that their offer to donate is free from coercion and that they are not seeking payment (Shaw 2019). One non-directed donor I spoke with recounted an experience of testimonial smothering as she talked about the difficulty of convincing people that her intention to become an anonymous donor was valid. She surmised that her initial appointment with a hospital renal department was double-booked because she was not expected to turn up, and then, after all the tests were done, which took "a very long time", she was told that the operation was not carried out at that particular hospital. Having gone through the entire process to determine donor suitability, the woman began inquiring at hospitals around New Zealand to see if any were willing to do the operation. She, "wrote a letter to [*New Zealand city*] Hospital and explained what I had done, and I got a very nasty letter back telling me that I was just after money for my kidney" (Shaw 2019). The string of micro-aggressions and invalidation this woman recalled, as evidenced by the quotation above, did not deter her. She did eventually donate a kidney as a non-directed donor, with another service provider at another New Zealand city.

Several of the non-directed donors in the study explained that passing as a genuine donor not only required 'persistence' but also meant saying the right thing to health care professionals and psychologists. To avoid appearing emotionally compromised, they explained that it was important to downplay emotion when communicating their donative intent to health care practitioners. This is not to say that they lacked reasons for wanting to become non-directed donors, but that their testimonial credibility largely rested on their ability to mobilize institutionally derived scripts to show that they fully comprehended the risks and benefits of their donative decision-making to medical professionals. Because of the longstanding perceived suspicion among the medical community regarding the existence of genuine altruism, living non-directed kidney donors go to great lengths to phrase their motivations using institutionally acceptable language, such as talking about their second kidney as a vital spare part that would go to waste if not donated (a perspective shared by many living directed

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donors), or by expressing their awareness of the physical impact of renal failure and dialysis on others' suffering (Shaw 2019). Consequently, non-directed kidney donors describe their donative decision-making in rational terms as non-emotional and carefully deliberated, having more to do with outcome than objectifying their moral identity as a good citizen.

For instance, one participant claimed that although she had "four or five different reasons" to donate, she could, for the purpose of convincing people it was the right thing to do, sum up her decision as a "simple, basic, logical equation" about functioning on one kidney and helping out if you can. Likewise, another participant stated, "I'm fairly clinical in my approach. […] I know what good it will do. I know I can live with one kidney, and I didn't need to ask anybody that, to make up my own mind." This reasoning works as a useful, expedient rhetoric to fit the dominant view of the human body as an assemblage of interchangeable parts, able to be exchanged with little or no psychosocial, emotional or existential impact. Prospective donors are guarded about saying they view their acts as symbolizing human connection during the psychological assessment process, for fear of jeopardizing their donative plans. While beliefs about metaphysical communion with other human beings may be salient, these ideals are not typically articulated as the key driver for donative intent. Their accounts suggest that they find an event to identify as a precipitant for their acts (for example, saying they once knew an acquaintance with end-stage renal failure or being able to live a full life with one kidney) because they are compelled to rationalize their motivations to fit dominant institutional logic.

7. Conclusion

This chapter discusses the significance of altruism and gift-of-life language as a cultural and institutional value motivating ethical practices of organ donation and transplantation in relation to gratitude as a moral imperative. As suggested, however, not all organ recipients tell the same story about their illness and transplantation experience, "with morally expected (appropriate) levels of gratitude" (O'Brien 2017: 293), nor do they frame their stories in uniform ways using gift-of-life terminology. How organ donors, donor families, and transplant recipients talk about their experiences of organ transfer in the context of patient-practitioner interactions and in public fora, and what they are permitted to say, is affected by the credibility they are afforded by health care professionals and the interpretative resources they have available, not only to articulate and make sense of their experiences, but also to be heard by those with epistemic authority. While the New Zealand study indicates that Intensivists and Transplantation specialists do not always resist epistemic humility with respect to patients' testimonies about gift-of-life terminology and expectations of gratitude (Shaw 2010, Shaw/Webb 2015), these understandings do not always translate to promotional and educational discourse or media discussion in the public domain. In order to create what Fricker calls "the positive space of epistemic justice" (2007: 7) and enhance the knowledge base and public understanding of organ donation and transplantation to assist the development of ethical guidelines and health policy discourse, we need to expand the conceptual toolkit explaining organ donation and transplantation (Shaw

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2015) so voices that do not conform to sanctioned ways of encountering and speaking about transplantation can be heard and adequately addressed.

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