

# Heart transplants: Identity disruption, bodily integrity and interconnectedness

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## Abstract

Of heart transplant recipients, 30 per cent report ongoing or episodic emotional issues post-transplant, which are not attributable to medications or pathophysiological changes. To this end, our team theorized that cardiac transplantation introduces pressing new questions about how patients incorporate a transplanted heart into their sense of self and how this impacts their identity. The work of Merleau-Ponty provided the theoretical underpinning for this project as it rationalizes how corporeal changes affect one's self and offer an innovative framework to access these complex aspects of living with a transplanted heart. We used visual methodology and recorded 25 semi-structured interviews videographically. Both visual and verbal data were analyzed at the same time in an iterative process. The most common theme was that participants expressed a disruption to their own identity and bodily integrity. Additionally, participants reported

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interconnectedness with the donor, even when the transplanted heart was perceived as an intruder or stranger. Finally, transplant recipients were very vivid in their descriptions and speculation of how they imagined the donor. Receiving an anonymous donor organ from a stranger often leaves the recipient with questions about who they themselves are now. Our study provides a nuanced understanding of heart transplant recipients' embodied experiences of self and identity. Insights gained are valuable to educate transplant professionals to develop new supportive interventions both pre- and post-transplant, and to improve the process of informed consent. Ultimately, such insights could be used to enable heart transplant recipients to incorporate the graft optimally over time, easing distress and improving recovery.

**Keywords**

heart transplant, identity, intercorporeality, qualitative research, visual methodology

**Background**

Current consensus among cardiologists and transplant specialists is that heart transplantation is the accepted therapy for individuals with end stage heart failure (Jessup et al., 2009). Post-transplantation, a well-recognized series of medical challenges arise, including rejection, hypertension and renal failure (Stehlik et al., 2012). Physiological outcomes, survival rates and quality of life have been extensively addressed in the biomedical literature and will not be the focus of this article (Grady et al., 2013; Shamaskin et al., 2012; Stehlik et al., 2012). Psychosocial challenges such as depression, emotional issues, poor return to work rates, anxiety and other forms of distress (Dew et al., 2005; Paris and White-Williams, 2005; Stehlik et al., 2012) have profound effects on the health and recovery of heart transplant recipients (Abbott et al., 2003; Dew and DiMartini, 2005; Mauthner et al., 2012). "Distress" frequently refers to psychiatric diagnoses such as depression, anxiety and psychosis (Abbott et al., 2003; Bunzel et al., 1990, 2005; Evangelista et al., 2003). Psychoanalytic studies of recipients' adjustment to an organ graft have identified common responses and coping mechanisms, such as overpowering feelings of gratitude to the donor family, guilt over the donor's death, denial and mourning of their own lost organ (Goetzmann, 2004; Inspector et al., 2004; Sanner, 2003). Some investigators have concluded that negative psychological responses to transplant and associated behavior may have direct and profound effects on the physiological integration of the graft, and consequently the health of recipients (Abbott et al., 2003; Inspector et al., 2004). These responses include non-adherence resulting in organ rejection as well as psychosomatic symptoms in which psychological distress is manifested in physical symptoms (Bunzel et al., 1990; Dew and DiMartini, 2005; Salvucci, 2004).

In contrast, other psychosocial/psychiatric research shows that many heart transplant recipients believe they have taken on characteristics of their donors (Bunzel et al., 1992a; Inspector et al., 2004; Sanner, 2003). An Israeli study of 35 male heart recipients demonstrated that almost 50% of the recipients had an explicit or secret impression of possibly

obtaining some of the donor's personality characteristics together with the heart (Inspector et al., 2004). In a study of 47 Viennese heart recipients, 21% of respondents said their personality had changed post-operatively, attributing this to either the trauma of nearly dying (15%) or the grafted heart itself (6%; Bunzel et al., 1992a). These findings, although concordant with first person accounts and popular media portrayals, have not been widely accepted by transplant professionals (Sanner, 2001, 2005).

Quantitative research has explored the challenges of living with a transplanted heart, including the evaluation of emotional distress, but it has not fully accounted for the occurrence of such outcomes (Bunzel et al., 1992b; Engle, 2001). As the majority of studies on these issues have used quantitative self-reported assessments (Burker et al., 2005; Paris and White-Williams, 2005), some researchers have turned to qualitative methods. Interview-based studies report recipients' fears and fantasies about their graft for instance, but stop short of suggesting appropriate interventions to address the impact on one's identity (Bunzel et al., 1992a; Inspector et al., 2004). Studies are also limited to a focus on audio transcripts of the interviews of what participants say. The novelty of our approach (Poole et al., 2009; Ross et al., 2010) is that we video record the interviews to capture and analyze what people say and how they communicate with their bodies during the interview (and the possible disconnect between the two). This videographic approach has produced findings that aligning with other published reports that point to high levels of embodied distress in participants who may regard the grafted organ as an intrusion into, a supplement to, or a replacement of, the self (Lock, 2002b; Sharp, 2006; Shaw, 2012; Waldby and Mitchell, 2006).

Some anthropologists (Manderson, 2011; Sharp, 1995) have investigated broader cultural attitudes towards the transplanted body, transformed identities and the boundaries of the self. One sociological study, consisting of interviews with 19 families who consented to donate a relative's organs, found that conceptions of embodiment—that is whether you *have* a body, or you *are* a body—varied among the sample, and in some cases had affected the decision to donate (Haddow, 2005). Joralemon (1995) frames popular discourse about organ transplantation and “procurement strategies” in terms of two familiar but opposed American values, altruism and individual rights (Joralemon, 1995). He argues that, as much as immune therapies suppress the body's instinct to attack foreign tissue, widespread intuitions about the inseparability of body and personal identity must be dampened in order for organ transplantation to attain social approval. The dominant medical rhetoric regards the procedure as an exchange of *spare parts*, which encourages recipients to reify and disassociate from their donors (Sanner, 2001; Sharp, 1995; Waldby and Mitchell, 2006). Similarly, Diprose's (2002) term *corporeal generosity* is used to contextualize how the body goes out to others with no expectation of anything in return. In contrast, however, large-scale awareness campaigns simultaneously promote organ donation by employing gift metaphors and appealing to beliefs about the deceased donor *living on* in recipients. Such opposing perspectives towards the meaning of the human body appear to conflict (Lock, 1995; Shildrick, 2013; Stone, 2005), and some critics have begun to unpack the unanticipated distress that such putative *corporeal generosity* on the part of donors may entail for the recipient (Diprose, 2002; Hird, 2007).

In an earlier study, 88% of heart transplant recipients demonstrated distress when asked questions about their transplant experience (Ross et al., 2010). Of those, 52%

demonstrated pervasive distress throughout the interview, which manifested itself as sadness, crying, anger and/or a flat and constricted affect (Ross et al., 2010). Lock (2002a, 2002b) found that among 30 transplant recipients interviewed, over half produced emotionally charged accounts about their donors, their organ and their transformed subjectivity. Rather than viewing the organ as a replacement part, some recipients continued to think of the organ as a different person inside of them, taking on a brand new identity post-transplant, for organ transplantation is a social engagement that shapes and ultimately transforms individuals' biographies (Lock, 2002a, 2002b). Similarly, Lesley Sharp (1995) interviewed 26 heart, lung and liver transplant recipients and reported that study participants were seeking out their donor's family and attempted to form relationships with them despite efforts of professionals to maintain anonymity on both sides; some had actively integrated the real or imagined personality of the donor into their post-transplant identity. Sharp (1995) concluded that *behavior* that is considered unusual or pathological may in fact be "a natural response to unnatural circumstances" (p. 361). Relatedly, Manderson (2011) conducted 300 in-depth interviews grounded in narrative epistemology to show how people re-establish the coherence of their bodies, identities and biographies after catastrophic bodily change, such as transplantation. Her work highlights the emotional difficulties of undergoing extensive surgical procedures and the subsequent transformed self.

Transplantation is neither a "neutral" nor an inconsequential experience for recipients (Bunzel et al., 1992b; Burkner et al., 2005; Paris and White-Williams, 2005). Shaw's (2012) study about transplant recipients' perceptions of the transplant process reported that recipients wanted to minimize the harm, distress, embarrassment and suffering that could result from their contact with donor families. Study participants expressed an inability to convey their gratitude for the gift of the donor, and found writing a thank you letter without reference to their selves, lives, work and families particularly difficult (Shaw, 2012). "In being both encouraged to think gratefully about their donors but constrained in how this emotion can be expressed, the letter becomes a potent source of dysphoria" (Poole et al., 2011: 621). As such, the extreme difficulty of writing the letter is a predictable expression of embodied interconnectedness (Poole et al., 2011). The assumption is that the transplant recipient's body and the grafted organ are irreducibly linked (Shildrick, 2008).

Contemporary French philosopher Jean-Luc Nancy (2000) writes, "never has the strangeness of my own identity ... touched me with such acuity," "for in me there is the intruder" or new heart (p. 9). That intruder is 20 years younger than he is, a "multiple stranger who intrudes upon his life" while unsettling notions of health and sickness, "self and other," as well as public and private (Nancy, 2000: 7–12). He describes his relationship with this "intruder" as "two I's, each one foreign to the other, yet touching" (Nancy, 2000: 13).

To summarize, most of the existing literature repeatedly identifies, but fails to fully explore, the identity disruption associated with incorporating a transplanted heart. The range of evidence supports the hypothesis that transplant recipients must incorporate transformed embodied identities as well as physiological and psychological changes. Canonical methods of health research have failed to provide insight: Psychosocial research has revealed the challenges of living with a transplanted heart and has measured

the prevalence of emotional distress but has not fully accounted for these outcomes (Bunzel et al., 1992b; Engle, 2001). Interview-based studies report recipients' fears and fantasies about their graft but lack explanations and stop short of suggesting appropriate interventions (Inspector et al., 2004; Laederach-Hofmann et al., 2002).

To address this critical gap in knowledge, our research team adopted a phenomenological understanding of embodiment and employed visual methodology to study transplant recipients' experiences of incorporating a transplanted heart. We theorized that heart transplantation has profound effects on recipients' identities and significantly shapes their lives. We focused on how heart transplant recipients (a) perceive their hearts, bodily integrity and personal identity and (b) imagine and speak about the donors. The work of Merleau-Ponty provided the theoretical underpinning for this project as it rationalizes how corporeal changes affect one's self and offers an innovative framework to access these complex aspects of living with a transplanted heart (Shildrick et al., 2009), which will be further explained in the following section.

## Theoretical underpinnings

Questions of identity and its disruption tap into a long tradition of philosophical inquiry around the self. Zeiler (2009) illuminates in her phenomenological work about illness and use of medical technology that "the self is embodied and in order to explore what it means to be a self, we need to explore what it means to have a particular body and what it means to live in a particular socio-cultural setting" (p. 96). Such concerns are beyond the remit of conventional biomedical ethics and empirical research. As Kraus (2000) remarks "empirical research lags behind such arguments, often missing the fractured self-experiences of the individual" and what they may teach us about what it is to be human in the 21st century. What is needed is a phenomenologically informed approach that engages with the complex meaning of heart transplantation for the recipient's ongoing experience of himself/herself as living-in-the-world.

Merleau-Ponty's (1962) philosophical phenomenology provides a highly relevant entry point into rethinking the meaning of heart transplantation, since he describes the world itself in corporeal terms. In this world, individuals are cast as participants in a web of what we would call intercorporeality that exposes the intersubjective and dynamic nature of human experience. For Merleau-Ponty (1962), our sense of self-identity comes into being only through our engagement with the world: "there is no inner man, man is in the world, and only in the world does he know himself" (p. xii). Moreover, he understands the *flesh of the world* (Merleau-Ponty, 1968) as a living web of interconnections in which we are all implicated, where, as he puts it, "the world of each opens upon that of the other" (p. 141), and from which the notion of *my self* emerges, not as a once-and-for-all identity, but as a never-ending process of becoming. Since we come into the world as bodies, human experience is necessarily embodied, temporal and spatial. On this view, because modes of embodiment are constitutive of both human identities and understandings of the world, to modify or transform the body is to modify the sense of self (Moss, 1989).

The phenomenological perspective runs entirely counter to the Cartesian machine model of the body that can yield transferable spare parts without loss to either the

donating or recipient *I* (Marcum, 2004). Additionally, phenomenology insists that the individual cannot be treated as an independent, free-standing entity. In place of the rigid and normatively framed autonomous self for whom the body is a possession that gives rise to property rights and questions of alienability, the phenomenological self is inseparable from, and only exists in virtue of, those who are others (Shildrick, 2008). The approach focuses not simply on the abstract interconnections between self and other, but more fundamentally on an intercorporeality in which bodies are woven together, as in the inherent reversibility of human touch (you touching me touching you), and the experiences of the maternal/fetal dyad (Shildrick, 2008). More specifically, the replacement of the beating hearts of terminally ill patients with donor grafts underscores the delicate intercorporeality of lived experience. Such an understanding of the embodied self lends credence to recipients' anecdotal reports of complex feelings of indebtedness, self-estrangement and alterity following a heart transplant (Shildrick, 2008). As contemporary phenomenologist Catherine Waldby (2002) puts it, "organ recipients are involved in the most direct and literal form of intercorporeality," and this brings their feelings of loss or transference of identity into sharp focus (p. 249).

## The study and method

Our team is not adopting phenomenology as a research method. We take the stance that phenomenology entails an orientation and a sensitivity to both text and body language, which are central to understanding and analysis (Kvigne et al., 2002). To this end, we conducted the study using visual methodology, which, like many visual studies, is oriented to Merleau-Ponty's (1962, 1973) understanding of embodiment as a matter of both mind and body, and of communication as both affective and verbal. Visual methodology is a distinct "body of sociological research concerned with the ways in which talk and bodily conduct feature in social interaction" (Heath, 1997: 267). Some psychological and medical sociology studies have assumed that investigators should treat the verbally reported experiences of participants as needing no further interpretation (Giorgi, 1970; Moustakas, 1994).

Our theoretical stance, grounded in Merleau-Ponty's work, requires a more detailed analysis and an equal attention to text and bodily comportment. As he understands it, human beings habitually engage in a complex body language of gestures, facial expression and movement which precedes speech itself, and on which final meaning depends (Merleau-Ponty, 1973). Both images and words, then, are essential to contextualize participants' emotions and experiences (Pink, 2006). In practice, this calls for an analytic approach whereby researchers make meaningful links between visual data, text and other objects. As Heath (2002) notes, "the more dramatic demonstrations" arise "in circumstances where there is a potential tension, or incongruity" recorded in the data between the content of transcribed excerpts and simultaneous embodied responses (p. 616). For example, individuals spoke about an event using upbeat language while being slouched over and lowering their tone of voice. As gesture and bodily conduct are used to "display, enact and (re)embody ... difficulties" (Heath, 2002: 597), this disjunction between body gesture and spoken word hints to the severity of the trouble being reported. Words and images contextualize each other and feature a set of different representations indicative

of feelings, reactions and experiences (Heath, 1997). We have already published a number of papers that outline how we have used video in *concert* with in-depth interviewing and field notes to examine the process of incorporating a transplanted heart, incongruities between participants' words and their embodied *expressive gestures* as well as *the obligation to say thank you* that befalls and befuddles many heart transplant recipients (Abbey et al., 2011; Poole et al., 2011; Ross et al., 2010). In our work, different sets of data represent various forms of knowledge, which are best explored by *examining their relation to one another* (Ross et al., 2010).

The study incorporates a qualitative, exploratory design and was approved by the Research Ethics Board (#07-0822-BE). This research was conducted in a single setting, within a large academic health science center in Canada. It is one of the largest cardiac transplant programs in the country and follows global organ donation and transplantation guidelines (Costanzo et al., 2010; Mehra et al., 2006; World Health Organization (WHO), 2010) with an ethnically and socio-economically diverse patient population. Patients are being cared for by a multidisciplinary team, composed of physicians, surgeons, advanced practice nurses and members of the psychosocial team. Patients being listed for heart transplant are offered a transplant mentor to provide support outside the program. Heart transplant recipients also have access to patient-led support programs.

A transplant nurse, not affiliated with the study, approached 29 heart transplant recipients who met inclusion criteria (age  $\geq 18$ , 1–10 years post-transplant, English speaking, medically stable). Patients were selected consecutively in clinic to minimize bias. One male and one female declined for unspecified reasons. Each patient signed an informed consent prior to participation. The final sample consisted of 25 medically stable post-heart-transplant recipients (70% male, mean age 53 years ( $\pm 13.8$ ); (range 18–72); mean time since transplant 4.1 years ( $\pm 2.4$ ); 17 Caucasian, 2 Black, 5 South Asian, 1 other), a number consistent with a sample size used in qualitative research (Heath, 1997).

Participants were offered the opportunity to be interviewed at their home or at a quiet room in the hospital away from the clinical setting. The choice of location was the participants' preference with 17 participants being interviewed in their homes, and 8 choosing to be interviewed at the hospital. The videographed interview times, regardless of location, ranged from 30 minutes to two and a half hours. All interviews were audio- and video-taped to capture voice and body language. Each participant was informed that the camera could be turned off at any time and instructed how to do so, although none of the participants opted to do so. In order to capture the embodied interaction of the interviewer and participant, the camera was purposely visible and static, a standard practice used in visual methodology (Heath, 1997).

Two advanced practice research nurses who had no involvement in the study participants' clinical care, conducted the interviews. Before each interview, 30 minutes were spent reviewing the confidentiality of the study, addressing participants' questions, and establishing rapport (Usher and Holmes, 1997). Participants were reminded that they could choose not to answer any question or stop the interview completely. Following conventions of semi-structured interviews, participants were asked open-ended questions and were invited to raise their own concerns. In all interviews, participants spoke openly, freely, often requiring very little prompting. For example, participants were

asked, *Has having a new heart changed the way you think about your body? Could you give me an example? Has having a heart transplant changed how you feel about yourself as a person? Could you tell me more about that? Some people say you become a different person after you receive a heart transplant. What is your opinion?* Techniques such as nodding, allowing silences, and asking questions such as “would you feel comfortable telling me more about that?” were employed as required (Graham, 1984). Detailed field notes were compiled by the interviewer following each session. Audio data were transcribed verbatim using coding conventions established by Poland and Pederson (1998) and Poland (2001).

The research team reviewed all interviews. Visual and verbal data were analyzed at the same time, in an iterative process. Coding of data was informed by visual methodologists Pink (2001, 2006), Heath (2002) and Heath et al. (2010). NVivo 8 was used to organize the data. In the first phase of data analysis, transcripts and videotapes were simultaneously reviewed and time-logged noting “key moments” (Pink, 2006). Key moments are particular events that are embodied responses such as *expressive gestures* that locate *areas of difficulty* on/in the body (e.g. hands on heart; pointing to the heart), *expressive artefacts* (e.g. open-necked shirts showing surgical scars) and *by the way syndrome*—which is a particular statement or gesture at the end of the interview that (re) asserted the significance or seriousness of a particular symptom/feeling (Heath, 2002; Heath et al., 2010). *Incongruities* such as *upgrades*, which represent speaking positively even when body comportment indicated distress, or *downgrades* when comportment appeared non-distressed while words revealed the opposite, were analyzed (Heath, 2002; Heath et al., 2010).

In the final phase of data analysis, the research team re-reviewed all transcripts and video recordings. At that stage, members of the research team met as a group to develop broad themes grounded in textual and audiovisual data. The themes were discussed and debated by the researchers in order to reach consensus before being collapsed into analytic categories. Lastly, these analytic categories were synthesized into a final set of themes which addressed the research question (Ross et al., 2010).

## Heart transplantation and “who am I” now

Advances in medical technologies are pushing recurrent philosophical concerns to new frontiers. In the case of organ transplants, the dominant socio-cultural understanding of the nature of the relation between body and self is challenged (Lock, 1995; Manderson, 2011; Sharp, 1995; Waldby and Mitchell, 2006) by a number of questions such as: *Where does one body end and another begin?* and *What happens to the specific self when organic components are exchanged?* Our aforementioned research process led to the identification of three major themes. The most common theme was that participants expressed a disruption to their own identity and bodily integrity. Additionally, participants reported interconnectedness with the donor, even when the transplanted heart was perceived as an intruder or stranger. Finally, transplant recipients were very vivid in their descriptions and speculation of how they imagined the donor. To that end, heart transplantation has profound effects on recipients’ identities and ultimately significantly shapes their lives.

### *Identity disruption and bodily integrity*

When participants were asked if they have experienced any changes in how they think or feel about themselves, 23 recipients spoke of changes to their former selves and having altered feelings. Having received a heart from another person, recipients question *who am I as a person?* A female teacher in her mid 20s had this to say:

What do you do when your friend has a heart transplant? They are alien to you. I became alien to all my friends. To expect them to understand my mood swings and understand the strangeness that is me that has come out of it.

A male social worker in his 30s who practiced in a healthcare facility stated,

For a long time I felt really ... almost like I wasn't me for a while ... I don't know, I just felt like, who am I? You know, there were all these emotions I was going through. Like that wasn't me ... like it was somebody else ... and you couldn't control it ... My heart is like its mine and somebody else.

A female recipient in her late 50s who felt no longer able to return to work attributed changes in her feelings towards her husband to receiving a male donor heart. She stated,

The only thing I told you changed my life, I don't feel no affections with some, with like my husband ... I'm not interested in having sex with my husband.

This comment is reflective of a substantive change in the recipient's own sense of identity.

In transplantation, the inherently contradictory point is both to replace some intrinsic part of the bodily interior with living organs taken from the body of another while ensuring the continued existence of an unchanged (recipient) self. In contrast, our findings of identity disruption and bodily integrity are illuminated by recipients' experiences of various degrees of an altered self—questioning who they are, describing their changed feelings towards a loved one—as a consequence of the assimilation of the foreign body parts. Merleau-Ponty's (1968) notion of “flesh” provides a highly relevant explanation by that there is visceral substance to intersubjective embodied perception. Not only does flesh encompass the space between transplant recipients and the donor organ, it also includes the various social fields in which these relations are enacted. What the notion of flesh illuminates is that transplant recipients' interconnectedness with the transplanted organ is grounded in embodied perceptions about the self within a particular social backdrop. Hence, receiving a heart is a transformatory process, deeply impacting how individuals are able to move forward, and ultimately reshaping their self.

For individual heart transplant recipients, the mismatch between normative and socio-cultural expectations of the integrity of the embodied self, and personal perceptions and experiences of a changed body, results in a form of *identity disruption*. As it is used here, the term denotes a mode of disturbance that may manifest physical or psychological symptoms, such as those associated with depression or anxiety, but is equally likely to operate at a subconscious level that may be rarely overtly acknowledged. Both recipients

and those around them are caught up in a powerful socio-cultural denial of self-embodiment that may effectively silence or displace any ontological unease or anxiety that the recipient feels. Nonetheless, despite that observation, psychological and emotional disruption may be at the root of a variety of phenomena ranging from an over-determined insistence that nothing has changed; a heightened anxiety about the risk of body contamination; a claim to kinship relations to donor families; and a widespread interest in the many narratives of transposed identities following transplant that pervade popular culture. It is not that identity disruption always has a negative expression, but that its manifestations signify points of disturbance to the cultural backdrop of an integrated or unitary sense of self.

### *Interconnectedness of recipient with donor*

In our study, participants were asked how they think and feel about their own heart, as well as their donor's heart. The immediate response of 18 participants to this question was to compare the heart to a machine, a carburetor and a spare part that can be easily exchanged with no further meaning attached to it. As their responses were further explored however, 15 of these participants displayed a variety of emotions such as sobbing and incongruous laughter, changes in bodily comportment such as turning away from the interviewer, and fidgeting or tensing of their body posture. Recipients spoke about an intrusion into their "sense of self" and some mourned their own biological heart.

The intrinsic connection that is created between the donor and the recipient by virtue of the transplant procedure was described by nine participants who felt that the heart—and therefore the donor—lived on within them. In keeping with our theoretical assumptions, any change to the body is ultimately a change to one's self. This raised pertinent questions about the *interconnectedness of recipient with donor*, which was ultimately manifested in participants in the form of distress and identity disruption. One participant stated: "... I felt I had an alien thing in me, or somebody else [heart].... I missed my old heart." Another transplant recipient described, "I feel as if another person's spirit is in me." Additional responses included "For a while I felt as if there was an alien in my body ... a foreign identity" and "... because I have somebody else's organ, and so to a certain point it is almost like a two-in-one ..." and "... I think one of the things I would say to them [donor family] is .... through your love and care .... the person that you lost is still living through me."

Many heart transplant recipients initially spoke about transplantation as though it was just an exchange of spare parts, a repair job with little consequence, like the replacement of an engine in a car. As we are reporting here, due to the interconnectedness of recipient with donor, it is ultimately of little surprise that struggles with one's individual identity arise, for where the machine model rhetoric refers to non-organic interchangeable spare parts, the actuality of heart transplantation is that what is surgically removed from one body and grafted into another is in fact a living organ (Shildrick, 2008). To that end, our study participants speak of aliens, spirits and foreign identities living on within them with little guidance on how to incorporate the new identity into their sense of self.

Although many serious illnesses entail a confrontation with death (Trainor and Ezer, 2000), only in the case of *cadaveric organ transplantation* do patients know that their

lifesaving operation depended on the death of another human being, part of whose body will or does reside in them. It is difficult to imagine a more potentially fraught corporeal relationship. Clinical anecdotal evidence suggests that it is common for heart transplant recipients to speculate about the provenance of their heart, claim to have taken on new characteristics and/or behaviors post-transplant, and feel a sense of kinship with their donors, despite the requirement of anonymity (Sanner, 2003, 2005). Some recipients go to great lengths to track down their donor's family, and vice versa (Casati et al., 1994; Sharp, 1995). Contemporary Western medicine still largely endorses a mechanistic, *replaceable parts* model of the body, and hence not only dismisses the existence of any donor–recipient bond, whether real or imaginary but any related difficulty or distress. Many recipients, however, seem to find the machine model inadequate and at odds with their experiences. This may be because they grapple with the fact that while the donor's heart grants them a *new lease on life*, their bodies also sustain a vital remnant of another body that would otherwise have ceased functioning and died. Some transplant professionals may undermine, ignore or are not prepared to work with the reality of these anxieties when they are articulated by patients (Sharp, 1995; Sylvia and Novak, 1997). There is some evidence suggesting that long-term survival rests on the ability of transplant professionals to better *hear*, acknowledge and respond to such anxieties (Brown et al., 2006).

### *Imagining and speculating about the donor*

In all, 14 participants had dreams and speculations about the donor. Participants talked about how the donor might have been better people than themselves. They speculated what kind of person the donor might have been, their likes and dislikes, and how this might affect their own dispositions and outlook on life in general. Frequently, however, participants seemed overwhelmed by their donor's identity. Moreover, receiving a heart transplant brings the most dramatic form of intercorporeality into stark focus and recipients struggle with combining self and other. A 70-year-old retired male stated, "... I think it's a better heart because maybe [he/she] was a better person than I." Throughout other interviews, comments included "I honestly don't know what difference it would make [to know the donor], because then all I am going to do is see a ghost at my bed ..." and 38-year-old worker reported,

I know it's just an organ, but somehow you feel that the person is somehow living on, ... not to that extent but, at least there is some part of them living in somebody else's body, yes, but it's now become mine.

Grounded in our phenomenological assumptions, the concern is not that the heart transplant disrupts an otherwise fitting narrative of *getting a new part* and moving on with life, but that any attempt to reduce the process to just a technical intervention is bound to fail (Sharp, 2006). In his work, *Phenomenology of Perception*, Merleau-Ponty (1962) continuously highlights the ambiguousness of experience and being human. For him, this is not a troubling aspect of human experience that is to be unpacked in philosophical thought, but "ambiguity is essential to human existence, and everything that we live or think always has several senses" (Merleau-Ponty, 1962: 172). Similarly in transplantation,

then, there is “a genius for ambiguity that might well serve to define man,” a particular embodied experience that is the source of what it means to be a recipient (Merleau-Ponty, 1962: 195). The difficulty of incorporating a transplanted heart should not be seen as an aberration but as a predictable expression of the phenomenological experience of embodied intersubjectivity, as in the ambiguity of touching and being touched (Merleau-Ponty, 1962; Shildrick, 2008). Our findings show that transplant recipients are distressed by their imaginations of the donor and struggle to make sense of this interconnectedness of embodied selves. From a phenomenological point of view, transplant recipients’ distress with coming to terms with intercorporeality is predictable.

## Re-examining clinical practice

Our study provides a nuanced understanding of heart transplant recipients’ embodied experiences of self and identity. Insights gained are valuable to educate transplant professionals to develop new supportive interventions both pre- and post-transplant, and to improve the process of informed consent. Ultimately, such insights could be used to enable heart transplant recipients to incorporate the graft optimally over time, easing distress and improving recovery.

Based on our findings, our health care team has started to change how we prepare potential heart transplant recipients. Most importantly, we have eliminated the rhetoric of the machine model as it may fuel psychological and emotional disturbances and potentially silence patients who are concerned about identity disruption or may exacerbate their identity disruption because it makes their concerns appear to be non-normative—that is, they are the only ones thinking about these things and everyone else just sees it as an exchange of pumps. As we have reported elsewhere, the difficulty for health care providers in truly understanding and supporting transplant patients requires innovative ways to prepare and counsel patients through the transplant process (Mauthner et al., 2012). We are advocating support networks that include other transplant recipients, family members and health care providers, as interpersonal relationships and interactions are more helpful and supportive through the transplant process (Mauthner et al., 2012). Our team highlighted that writing a thank-you letter is not a neutral experience for heart transplant recipients (Poole et al., 2011). We have started to rethink the obligatory practice of writing an anonymous thank-you letter to the donor family and have recommended the implementation of additional support for the recipient through this process. Given the qualitative design of this study, we anticipate that transplant recipients in comparable situations will have similar experiences, and therefore, the findings will have relevance for other transplant programs. To that end, we continuously strive to educate new transplant providers about the existential aspects of the embodied self and the potential of identity disruption.

## Conclusion

Identity disruption manifesting as distress occurs frequently after heart transplantation regardless of how patients perceive their transplanted heart or their donor. Biomedical and surgical practices rely on the notion that the body can be remolded without

consequences to the embodied self. In contrast to this dominant Cartesian dichotomy, our work with transplant recipients insists that the phenomenological self is always embodied, and that embodiment is undeniably the continuing condition of being a self at all. The reality of transplant surgery is that what is cut from one body and grafted into another is a living organ, and as such the dominant rhetoric of exchangeable spare parts that denies the incorporation of the transplanted heart into the recipient's embodied self provokes distress. The prevalence of identity disruption seen in this study emphasizes the importance of phenomenologically informed audio/visual methodology. Based on our findings, current approaches to the informed consent process need to be revisited in order to include information about the potential risk of identity disruption. More importantly yet, if heart transplant professionals are to fully support recipients post-transplant, they should encourage rather than repress the expression of the understandable anxieties and sense of strangeness that so many recipients experience.

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