## **Entangled Bodies**

# Art, Identity and Intercorporeality

Edited by

**Tammer El-Sheikh** 

York University

Series in Sociology
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#### Introduction

## Tammer El-Sheikh York University

LIFE magazine's 15 December 1967 cover photo shows Louis Washkansky, the first-ever recipient of a transplanted heart, smiling with some effort after regaining consciousness in his hospital bed. The headline—"Gift of a Human Heart: A dying man lives with a dead girl's heart"—introduced a philosophical problem and a language that would frame heart transplantation for years to come. To be sure, the rhetoric of gifting continues to provide a comforting but hasty reply to difficulties raised by transplantation in regard to its production of hybrid identities. In this article, the gift-giving scenario maintains a tidy boundary between Washkansky and his donor, Denise Anne Darvall, protecting readers from the full impact of the proposition: a "man lives with a dead girl's heart." In the illustrated multi-page feature that follows, the South African man's operation is cast, a few days before Christmas, as a miraculous act of generosity and self-sacrifice. That this story unfolded in apartheid South Africa, in a settler-colonial situation where the very definition of humanity was daily contested at the level of policy, policing and resistance lay beyond the scope of LIFE's human interest and popular science piece. If the notion of a gift papers over philosophical problems, it also diverts attention from social and political determinants of identity, which have consequences for the practice of transplantation. What is a human and who decides? Who is given a second chance at life, and who grants that chance? What does it mean to have a body, and to share one's body with others?

Hybrid Bodies takes a critical view of the science, history, and culture of transplantation that followed this inaugural moment in 1967 to answer these and other questions of general, rather than merely journalistic, human interest. Working in and across the fields of cardiology, nursing, psychiatry, bioethics, sociology, art, and art history, the members of Hybrid Bodies have, in their tenyears-plus collaboration, endeavoured to bring to light the complexity of heart transplantation for recipients and donor families. They have also been cautious to not overexpose their subject(s) and to respect the limits of our understanding in the face of the most profound exchanges imaginable between selves and others.

<sup>&</sup>lt;sup>1</sup> "The Gift of a Heart," LIFE, 15 December 1967, 24–31.

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This volume collects their thoughts on this journey and on what it might mean, in the case of transplantation and beyond, to merge with another.

It is, above all, to those touched by the culture and experience of transplantation that this volume is addressed. The euphoria of that moment in 1967 is indicated in the smiles, visible behind the masks, of the medical professionals to either side of Mr. Washkansky. Since 1967, this mood has been tempered by research, much of it generated by members of Hybrid Bodies on recipients' and donor families' struggles with various types of grief and identity disruption. The gap between the great heights and fast pace of biomedical innovation, and the difficult, slow-moving knowledge that arises out of the experience of giving and receiving a heart, has been a fertile one for Hybrid Bodies. The poles are two sides of a coin whose ultimate value is unknown. Nevertheless, by attempting to invoke that value and give an account of the currency to which it attaches, the Hybrid Bodies artists and researchers consider a full range of human capacities—to care, to think and create, to harm, to act in advance of reflection, and to destroy, to give thanks, and to form bonds of kinship.

Representing a stubbornly unknowable human drama with stolen photographic clarity was the *modus operandi* of *LIFE* magazine. In that issue from 1967, the drama unfolds within a deceptively clear snapshot of the times. Beyond the cover story, a wider, cultural context for heart transplantation with clear moral overtones is suggested. In the pages following Washkansky's story, readers are confronted by a paranoid feature on "The Season for Shoplifting," in which surveillance stills capture "a drug addict lifting a sweater," "two teenagers pocketing lipsticks," and "a mother stealing crayons." In contrast to the heroism of the world's first heart transplant, these anecdotes paint a picture of human desperation, greed, and opportunism—darker features of our species' nature which are also a part of the cultural imaginary of transplantation. The proximity of these stories in the magazine encourages a crossing of wires, or of thinking about transplantation, in terms of theft and, more specifically, of theft in terms of giving—of body snatchers in the operating room and Robin Hood in the shopping mall. Further resonances between heart transplantation and the wider culture of which it is a part come through in the magazine issue's reviews of the film Guess Who's Coming to Dinner

<sup>&</sup>lt;sup>2</sup> On identity disruption post-transplant, see: Heather Ross et al., "What they say versus what we see: 'hidden' distress and impaired quality of life in heart transplant recipients," *Journal of Heart and Lung Transplantation* 29, no. 10 (2010): 1142–49. On forms of grief, see: Jennifer Poole et al., "Grief and loss for patients before and after heart transplant," *Heart and Lung: The Journal of Cardiopulmonary and Acute Care* 45, no. 3 (2016): 193–98.

<sup>&</sup>lt;sup>3</sup> Chris Welles, "The Season for Shoplifting," LIFE, 15 December 1967, 66–74.

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(1967) and the children's book *Where the Wild Things Are* (1963).<sup>4</sup> The fears of imposters and monsters that drive works like these are expressed as well in the narratives of transplant recipients and donor families. Perhaps most resonant for Hybrid Bodies is the issue's story on Joseph Cornell, an artist whose enigmatic "universes stored in boxes" would not be out of place in an exhibition alongside pieces by the group's artists.<sup>5</sup> Such an exhibition might well borrow the title of artist Dana Dal Bo's contribution to this volume: "Everybody Has a Box."

Looking back, the editors of LIFE appear to have been participants in an affirmative culture that could absorb the biomedical innovation of heart transplantation and frame it within an existing moral economy before the implications of the procedure were known. The article suggests as much in its opening paragraph: "a 30-man team worked nearly five hours to perform the operation which, regardless of the ultimate outcome, is a historic achievement."6 Hybrid Bodies is more circumspect about this achievement, even as many of its members advance the science that was uncritically celebrated in LIFE. The protagonists as well are different. The "30-man" team of 1967 contrasts sharply with the mostly female team of Hybrid Bodies. Hybrid Bodies encompasses two other research groups headed by cardiologist Dr. Heather Ross: The Process of Incorporating a Transplanted Heart (PITH) and Gifting Life: Exploring Donor Families' Embodied Responses to Anonymous Organ Donation in Canada (GOLA). Along with nursing scholar Dr. Patricia McKeever and feminist philosopher Dr. Margrit Shildrick, Ross would lead these groups into a collaboration with transplant psychiatrist Dr. Susan Abbey, sociologist Dr. Jennifer Poole, nurse practitioner Enza DeLuca, and nursing scholar Oliver Mauthner, as well as an international group of artists including Ingrid Bachmann, Emily Jan, Dana Dal Bo, Alexa Wright, and Andrew Carnie. For all its interdisciplinary complexity, the focus of the Hybrid Bodies group is simple: to consider the experiences of heart transplant recipients and donor families as given through video-recorded interviews with them in their homes. Abandoning the usual measures for assessing post-transplant "quality of life," the group analyzed verbal and non-verbal messages in the videos to better understand the impact of transplantation on senses of identity, kinship, personal responsibility,

<sup>&</sup>lt;sup>4</sup> Robert Phelps, "The Hidden World of Maurice Sendak," and Richard Schickel, "Guess Who's Coming to Dinner with Spencer Tracy and Katherine Hepburn," *LIFE*, 15 December 1967, 8 and 16.

<sup>&</sup>lt;sup>5</sup> David Bourdon, "Boxed Art of Joseph Cornell," LIFE, 15 December 1967, 52–63.

<sup>&</sup>lt;sup>6</sup> "The Gift of a Heart," 24.

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and feelings of obligation for both recipients and donor families.<sup>7</sup> With a theoretical grounding in anthropologist Marcel Mauss's work on reciprocity in gift-giving relations and philosopher Maurice Merleau-Ponty's writings on how perception, communication, and personal identity proceed from a primary reckoning with embodiment, the group's conversations maintained a focus on details of interviewee testimony that slipped through the cracks in more conventional research on transplantation.<sup>8</sup> The group's initial findings, after pouring over hours upon hours of heart-wrenching video testimony, break apart the image of success conveyed in the staged smiles and triumphant headline of the *LIFE* story. Positive verbal accounts of "successful" transplants from recipients and donor families were contradicted by grief-stricken facial expressions, comportment, and gesture. And the "gift of a human heart" carried with it, in an overwhelming number of cases, unresolved feelings of obligation, guilt, and alienation, especially as recipients and donor families grappled with the prospect of writing and receiving "thank-you" letters.<sup>9</sup>

The artists in Hybrid Bodies were tasked with translating these findings and responding creatively to the videos from which they were drawn. Ross's goal of utilizing the videos to "properly see what patients were saying" was achieved by visual artists, who were entrusted with the task precisely because of their exceptional powers of seeing with sensitivity, intelligence, and empathy. Working in various media, the artists processed the raw data generated by the PITH and GOLA research groups and reworked the testimony of recipients and donor families imaginatively to isolate its emotional charge and amplify the groups' most fundamental questions: Who are we? In what sense are we together and apart? How do we change and remain the same through traumatic experiences? Gathered around a table in a hospital room to discuss the videos, group members conducted their work on a level playing field, cutting through what essayist Sviri

<sup>&</sup>lt;sup>7</sup> On the benefits of this qualitative approach, see: Susan E. Abbey et al., "Qualitative interviews vs standardized self-reporting questionnaires in assessing quality of life in heart transplant recipients," *Journal of Heart and Lung Transplantation* 30, no. 8 (2011): 963–66. 
<sup>8</sup> The key texts for the group were: Maurice Merleau-Ponty, *Phenomenology of Perception*, trans. Colin Smith (London: Routledge, 1962); and Marcel Mauss, *The Gift: Forms and Functions of Exchange in Archaic Societies*, trans. Ian Cunnison (London: Cohen and West, 1966).

<sup>&</sup>lt;sup>9</sup> Jennifer M. Poole et al., "The Obligation to Say 'Thank you': Heart Transplant Recipients' Experience of Writing to the Donor Family," *American Journal of Transplantation* 11, no. 3 (2011): 619–22. On contradictory verbal and non-verbal messaging, see: Ross et al., "What they say versus what we see"; and on forms of grief, see: Poole et al., "Grief and loss for patients before and after heart transplant."

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Hustvedt decries as a patriarchal, hierarchical distinction between the "squishy" arts and humanities, and the "hard" sciences. 10

To reflect the collaborative and transdisciplinary spirit of Hybrid Bodies, this book's contributions from artists, scientists, and scholars are organized into four thematic parts: Part One: Travelling Concepts; Part Two: Scenes of Hybridity; Part Three: Listening; and Part Four: Place, Space, and Location. In Part One, essays by a cardiologist (Heather Ross), an artist (Ingrid Bachmann), and a curator (Hannah Redler-Hawes) clarify what is at stake in the transfer and translation of concepts from the field of medical science into the fields of art and exhibitionmaking. In Part Two, the guiding theme of hybridity in the project is presented in a script written by an artist (Alexa Wright) and in essays by a feminist philosopher (Margrit Shildrick) and an art historian (Tammer El-Sheikh). Part Three, as well, is organized around a single, crucial topic and practice for the group: listening. In it, we hear from a transplant psychiatrist (Susan Abbey) about the clinical practice of listening, and from two artists (Emily Jan and Dana Dal Bo) about especially arresting words, tones, and stories captured in the interviews with recipients and donor families. In Part Four, the theme of space in Hybrid Bodies brings together reflections of a nurse practitioner (Enza De Luca) on the homes of donor families and recipients; a sociologist (Jennifer Poole) on the inscription of race, class, and gender within the spaces of advanced medical science; a literary scholar (Donna McCormack) on the place of transplantation in the science fiction imaginary; and an artist (Andrew Carnie) on the experience of working between the artist's studio and the scientific community's comfort zones of lab, operating theatre, and classroom.

Of all the contributors to this volume, literary scholar Donna McCormack is the only non-member of the Hybrid Bodies group. Her contribution here reflects the group's longstanding but hitherto unexplored interest in the relationship between the culture of transplantation and the science fiction imaginary. I was also a latecomer to the group, having joined in 2015, after the first 5-year phase of research and creation, specifically to write about the work of its artists. I met Dr. McCormack in 2018 at a Winchester Gallery conference and works-in-progress exhibition organized by artists and original Hybrid Bodies members Andrew Carnie and Alexa Wright. The co-curator of that aptly titled exhibition, *Chiasma*, was Hannah Redler-Hawes, yet another latecomer to the group. Her vital contribution to this volume conveys the excitement of joining a wildly

 $<sup>^{10}</sup>$  For an account of Hustvedt's confrontation with this belief system, see Wendy Smith, "'A Woman Looking at Men Looking at Women' upends notion of the superiority of scientific truths over artistic ones," *Boston Globe*, 22 December 2016,

https://www.bostonglobe.com/arts/2016/12/22/upending-notion-superiority-objective-scientific-truths-over-squishy-artistic-ones/VIhzit3M3NI4ANSIEPabqN/story.html.

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diverse yet focused community, and of seeking for it an adequate, public-facing configuration. The gathering in Winchester was formative for me in my role as an art historian working alongside such an impressive team. Hearing from Dr. McCormack and others, whose creative and scholarly work has not made it into this volume, impressed upon me the importance of representing Hybrid Bodies as a mobile and expansive entity, with constituencies in various fields, on several continents, and across a spectrum of abilities. Meetings like the one in Winchester, with members of the transplant community, medical practitioners, artists, writers, and makers of various kinds, have animated the work of Hybrid Bodies from its inception. My hope is that this volume reflects the strong personal, professional, and intellectual bonds that hold this community together and propel it into the future.

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## Part One: **Travelling Concepts**

In Part One, a relationship between the artists and scientists in Hybrid Bodies is established. In a personal register, Dr. Heather Ross recounts her experience of coming to the discipline of cardiology and then, after a harrowing encounter with a transplant recipient, deciding to embark on a critical and interdisciplinary approach to the study and clinical practice of heart transplantation. The turning point in Dr. Ross's story, about a healthy recipient who attempted to remove his heart after a successful transplant, introduces a key problem for both the artists and the scientists in the group: if biomedical indicators of "success" don't capture the profound impacts of incorporating another's heart, how might a fuller picture of the experience be secured? The challenge of "knowledge transfer" between science and art is taken up by artist Ingrid Bachmann in her essay on mixed/new media works by Kader Attia and Anna Hawkins, which deal with the themes of restoration and repair. In this dialogue between artists, the language of transplantation—of cuts, wounds, and sutures—moves outside of the field of medicine to analyze art works that deal with the normative beauty of classical Greek sculpture and the violence of colonial occupation. Bachmann's essay ends on a provocative note about engaging concepts drawn from beyond our disciplines and cultural contexts to grapple with the experience of hybridity. In Hannah Redler-Hawes's essay, the art and science exchange so integral to Hybrid Bodies is taken up from a curatorial point of view. The challenge she reflects on is one that has preoccupied the group and, given the group's work, that possesses a deeply ethical dimension. Zooming out from the task of knowledge transfer between scientists and artists, Redler-Hawes considers how the stories of donor families and recipients may be communicated effectively and sensitively to the gallery-going public. She finds that this larger task of transfer, in the exhibition context, is enabled by trusting relationships, both within the group and between the group and its audiences.

#### Chapter 1

### In the Beginning

## Heather Ross *University of Toronto*

#### Background

Heart failure (HF), a chronic condition, is a growing epidemic in Canada. A common definition of HF is that the heart is no longer able to pump adequately to meet the needs of the body. The commonest cause of HF is coronary artery disease including heart attacks. Other common causes include high blood pressure, valvular heart disease, inherited heart conditions, and toxin-mediated heart disease (e.g. chemotherapy, alcohol, cocaine). One million Canadians have HF. Globally, the incidence of HF is expected to increase by 25% by 2030. Once HF is diagnosed it is associated with significant morbidity and mortality, with an average life expectancy of 2.1 years after diagnosis. Patients' quality of life is dramatically impacted with fatigue, swelling of the legs, and difficulty breathing especially with activity or at night. Palpitations, or racing of the heart, is common and there is an increased risk of sudden death due to arrhythmia. Once patients transition to advanced heart failure their symptoms are present at rest or with only minimal activity. Patients liken this to drowning. At this point, patients face a 50% risk of dying in six months. There is no cure. Heart transplantation is the treatment of choice for selected patients with advanced heart failure. There are approximately 50,000 Canadians with advanced HF, yet we only do 200 to 250 heart transplants each year. Hence, the need for organ donors far outstrips the availability. Recipients therefore often equate receiving a heart transplant with having won the "lottery of life." By necessity, someone must die (the donor) for a heart transplant to occur.

The average life expectancy after heart transplantation is 11 years, and if a recipient survives the first year, then their conditional life expectancy is 14 to 15 years. Standard biomedical outcomes are excellent for heart transplant recipients. The vast majority will have complete resolution of shortness of breath and fatigue and can resume normal daily activities, including travel, work, and sex. However, recipients must follow a strict regimen of medications and follow-up tests including heart biopsies, ultrasounds, scans, and angiograms. Psychological

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distress is reported in approximately 21% of patients post heart transplant, including reports of PTSD.<sup>1</sup>

#### The Genesis of the Hybrid Bodies Project

How did I get to Hybrid Bodies from a strictly quantitative biomedical research background? My background is fairly typical of someone who goes into medicine. I did an undergraduate degree in biology, focusing on molecular genetics. During medical school, I was fortunate to work at the Terry Fox Centre in Vancouver on stem cell biology. I then followed traditional medicine residency training and a fellowship in cardiology. My postdoctoral training was at Stanford, where I focused on a PCR-based project to determine molecular markers and risk for rejection in heart transplant recipients. Eventually, after 18 years of post-secondary school training, I accepted a job in Toronto to run the Advanced Heart Failure and Heart Transplant program. Until that time, all 18 years of my training had been underpinned by mechanistic, Cartesian, quantitative work.

In 2007, the real world intervened. As they say, life is what happens to you when you are busy making plans. My basic science training did not prepare me for what it would be like to be a care provider to heart transplant recipients, especially if you are prepared to listen.

The day in question occurred when I was called to the coronary intensive care unit, as one of my heart transplant recipients had tried to cut their heart out with a knife—a life-changing moment for both of us. It was in that moment that all my traditional training failed to provide me with an explanation for this act. I was cast adrift. How could I reconcile the distress this patient felt, that led them to try to remove their life-saving, life-thriving heart transplant?

Not soon thereafter, I was invited to speak at an event organized by Dr. Pat McKeever. I gave the quintessential medical talk, all PowerPoint figures, animation, statistics, and clinical trials. I sat down to listen to the next speaker, Dr. Margrit Shildrick, a feminist philosopher. My first thought was: what was the organizer thinking, putting the two of us as back-to-back speakers? As Margrit began to talk, I was mesmerized. Her talk was on corporeal cuts in conjoined twins. She specifically spoke about where the cut is made. As I listened to her, I remembered my encounter with the recipient who had tried to carve his new heart out. Epiphany!

Pat, Margrit, and I went out for lunch a few days later and the project known as the Process of Incorporating a Transplanted Heart (PITH) began. We gathered an

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<sup>&</sup>lt;sup>1</sup> M. A. Dew et al., "Profiles and predictors of the course of psychological distress across four years after heart transplantation," *Psychological Medicine* 35 (2005): 1215–17.

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