My Heart, Myself: Using a Phenomenological Model to Understand the Body

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Abstract

In phenomenology, the topic of inquiry is lived human experience and the test for what is real or important in the world is what is real or important to the individual. The study of heart transplantation has to do with the connection between the body and the self. The biomechanical model used in Western medicine emphasizes that the heart is just a pump, and a heart transplant is a purely physical intervention, albeit a severe one. Recipients' experiences of their heart transplants repeatedly indicate that this model is not adequate for everyone and that a phenomenological approach might prove much more fitting. The range of unexpected and unexplained changes described by heart transplant recipients – from tastes inherited from their donors to sudden depression and loss of functionality – can all be accounted for by a paradigm that refuses to separate the body and the self into crude opposites. In fact, phenomenology would predict that a person who had been rescued from the brink of death by a massive bodily intrusion would experience some form of disruption to the self.

Introduction

Historically, Western medicine has approached the patient and his or her body as distinct entities. The conception of the body as a machine – a material, non-animated substance, distinct from the intangible, animated 'self' is often described as "Cartesian" because of its most influential articulation by René Descartes in the 17th Century. While classical dualism has been challenged over the centuries by many schools of philosophical thought, the biomechanical model of the body is so entrenched in Western medical practice as to be nearly invisible.[1] In recent years, however, healthcare has evolved with practitioners taking into account important connections between a patient's physical, mental, and social health. As will be discussed, the example of heart transplantation makes clear that patients' experiences of their bodies might diverge considerably from the traditional medical model. A phenomenological understanding of the body and of the self can offer a medical model that resonates better with some patients' experiences than the historical biomechanical approach.

Body and Self

The argument of this paper hinges on how we conceptualize a very familiar item: the human body. What is a model of the body? A distinction in the German language which, like so many German expressions, resists direct translation into English, crystallizes the two models discussed here. The word "body" in German is referenced by two words, ***Leib*** and ***Körper***. Despite their apparent synonymy, the words carry distinct connotations. To speak of a ***Körper*** is to speak of a material thing: a body, a corpse, a specimen, a machine. A ***Körper*** is composed of limbs and muscles, organs and veins – nothing more. ***Körper*** gives rise to German expressions describing the merely physical: ***Körpermasse*** (measurements) and ***Körperpflege*** (hygiene) are examples. To speak of a ***Leib***, by contrast, is to speak of a living body, usually one's own.[2] It denotes, beyond the physical aspects of a particular substance, the aspects of the individual. Derived from the word for "life" (Leben), ***Leib*** is the source of human experience, in that the physical and non-physical dimensions of personhood are inseparable.

There are other ways of conceptualizing the body, but this distinction is useful because it cuts to the essence of a centuries-old debate in Western philosophy. What or where, exactly, is the 'self'? Is the self an intangible entity, a soul trapped inside a material body? Or is the self composed of both material and non-material elements? If so, how do they communicate with and affect one another? Phenomenology examines the relationship between the self and the body.

What is Phenomenology?

Phenomenology is the term for a variety of branches of philosophical inquiry whose overarching goal is to understand the world as it is experienced by persons. It questions the Western philosophical presumption of 'objectivity' or mind-independent truth. Two important features of this tradition are worth noting here. The first involves how phenomenology understands and pursues 'knowledge' and 'truth.' The second pertains to the corporeality of the world and human experience.

First, as argued by Edmund Husserl, the first systematic phenomenologist, rather than attempting to verify or uncover 'truths' that are by definition unverifiable or inaccessible to human perception, one must take the perceiving, conscious individual as the starting point for knowledge. There is no privileged realm of truth beyond the subjective. This is not to say that scientific (objective) inquiry is futile, but rather that no amount of scientific evidence can undermine the reality of one's personal experiences, however contradictory the two may be. This position differs considerably from that of rationalists like Descartes and Kant, for whom the objects of one's perception have dubious existence until corroborated by more 'reliable' evidence, such as pure reason. In phenomenology, the very fact of a thing

having been perceived – whether through sight, touch, or any other sense – is enough to lend it unquestioned metaphysical legitimacy. In phenomenology, "even the most improbable *phenomena* [perceived things] are immediately accepted as real."[3]

Second, as becomes more central in the phenomenology of Maurice Merleau-Ponty, human experience and our ways of interacting with the world are inescapably corporeal.[4] Since we come into the world as embodied (rather than as, say, incorporeal spirits or disembodied brains), human experience is necessarily corporeal. Our experience of embodiment is thus constitutive of both our identities and our understanding of the world around us. To modify the body is tantamount to modifying the self. The physical and non-physical elements of life are inextricably integrated, to the point that even making the distinction might seem spurious.

The phenomenological view of human experience yields a model of the body that differs powerfully from the received dualist model attributed to Descartes. Whereas Descartes describes the mind and body as radically distinct substances, phenomenology casts the body and mind in monist terms. In short, the biomechanical model of the body aligns with the term *Körper*, and the phenomenological model with the term *Leib*.

Heart Transplantation and Perception of Body and Self

The difference between thinking about the body as Körper or as Leib can be borne out by an investigation of one of the most sophisticated medical interventions ever devised. Heart transplantation has been practiced routinely since the 1960s and is now the universally accepted therapy, where available, for end-stage heart failure. Tremendous advances in medicine, including the development of the immunosuppressive drugs, have allowed heart transplant recipients to avert rejection of the new organ, and survive an average of almost 10 years post-transplant.[5] In fact, the medical management of heart transplantation is so advanced that much of the research now focuses on how to improve recipients' quality of life.

The medical science that enables heart transplantation not only relies upon, but might be said to epitomize, the biomechanical model of the body. The deft exchange of human organs in the service of extending natural life is a triumph of contemporary Western medicine. It displays an intimate understanding of the parts and processes that fuel the human machine, and moreover, effectively quells the skeptic's intuitions that there is more to the body than the blood and tissues familiar to surgeons. Contrary to idealist threads in popular culture and parlance, transplantation seems to prove that the heart is just a pump; replace a swollen, beleaguered, sickly one with a working version, and morbidly-ill patients might enjoy near-perfect health. Why, then, should many heart transplant recipients feel that Cartesian dualism completely misses the point?

The challenges associated with recovering from heart transplant surgery are numerous and complex. The literature on this topic abounds; from the risk of rejection and higher rates of cancer, to psychosocial adaptation and the likelihood of returning to work, the changes in the life of a transplant recipient are well-documented and extend farther than the obvious impact of a major surgery. But a closer inspection of heart recipients' experiences suggests that something less transparent might also be at work. Studies and anecdotal evidence show that a significant number of patients – approximately 20% on most counts – suffer from a form of psychological or emotional distress post-transplant that is uncorrelated to clinical measures of health, and may appear or be exacerbated at any time, often to the detriment of the patient's functionality, relationships, and happiness.[6,7,8] While insights into the sources of such distress are limited and scattered at best, the evidence for its existence is uncontroversial. This negative outcome is hardly investigated in the leading journals and publications on transplant medicine, possibly because of its apparent immunity to clinical interventions and physiological explanations. Nonetheless, some sociologists and anthropologists, approaching the study of heart transplantation with non-medical paradigms, have shown great interest in recording and understanding recipients' experiences.[9,10,11,12] Their studies contain recurring accounts of patients believing things about their bodies that seem to defy the mechanistic model. Specifically, many heart transplant recipients are unwilling or unable to accept that their diseased organ was replaced with a "spare part," the way a true machine would be fixed. They feel that the transplant, far from being a strictly material intervention, was simultaneously an intrusion into their very identity.

The most obvious evidence for this conflation of bodily and non-bodily sequelae is found in several reports of heart transplant recipients taking on characteristics of their donors. These reports are found in medical journals, anecdotal evidence at transplant centres, and first-person accounts. Psychiatric and psychosocial studies of heart transplantation have begun to expose the prevalence of these experiences. In one Israeli study of 35 male heart recipients, over half of the participants were found to "[endorse] fantasies and [display] magical thinking."[13]

Although "all recipients possessed a scientific knowledge of the anatomy and physiological significance of the heart," almost 50% of the recipients "had an overt or covert notion of potentially acquiring some of the donor's personality characteristics along with the heart." In another study of 47 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%).[14] The investigators concluded that "there seem to be severe problems regarding graft incorporation, which are based on the age-old idea of the heart as a centre that houses feelings and forms the personality."

These types of studies begin to identify a mismatch between the model of the body proffered by transplant physicians, and the actual experiences of heart transplant recipients. It is first-person testimonies that make the extent of the disjunction most apparent. Heart transplant recipients describe a range of unexpected changes resulting from their operation, from new appetites and dispositions to anxieties and nightmares, which quantitative self-reporting measures fail to capture in their complexity. Convinced of a

kinship that transcends mechanical replacements, some recipients search out their donor's families and attempt to form relationships with them, and vice-versa, despite efforts to keep both anonymous. Still others actively integrate the real or imagined personality of the donor into their new post-transplant identity.[9,15] It is clear that the strictly physical and impersonal explanation of heart replacement, and the associated expectation that recipients will resume "normal" lives post-transplant, fails to account for many recipients whose experiences involve metaphysical and interpersonal dimensions, as well.

Personal Perspectives

Claire Sylvia catalogues a litany of such experiences in her autobiography, *A Change of Heart.*[16] Following her heart-lung transplant, she had vivid dreams about her donor (his name, his age, how he died), which revealed information that was subsequently verified, and she developed new tastes and interests that paralleled her donor's. Despite the protestations of her transplant doctor, she located her donor's family, with whom she forged deep and long-lasting bonds. Indeed, her donor's family, the parents and siblings of a reckless 18 year-old boy, confirmed that the 47 year-old dancer's new appreciation of beer, green peppers, and Kentucky Fried Chicken were characteristics of their deceased relative. But not all of Sylvia's post-operative changes were thereby explained. Immediately after her transplant, she experienced a period of depression and alienation that the assurances of health care practitioners did nothing to appease:

> *I didn't know who I was or what I was doing here. My body, the nurses assured me, was doing fine...But it wasn't my body that concerned me. It was everything else...I was going through the early stages of an identity crisis.*

In her subsequent work as a support group organizer for other heart transplant recipients, Sylvia discovered that her experiences were far from anomalous; many fellow recipients she met had experienced troubling ruptures in their personal identity, dreaming scenes that appeared to belong to another person's life, and struggling to incorporate a stranger's organ into their psychic worlds, as well as into their bodies. "In different ways," she summarized, "we all believed that receiving a new heart had affected and even changed our identities."

The personal disruption wrought by heart transplantation can take numerous forms. For contemporary French philosopher and heart transplant recipient, Jean-Luc Nancy, the procedure and its aftermath were characterized by feelings of "strangeness" and "foreignness."[17] In Nancy's autobiographical investigation *L'Intrus* ("The Intruder" or "The Intrusion"), he describes the unsettling dissolution of familiar categories – health and sickness, self and others, life and death – that rendered his life-saving operation self-alienating, as well as remedial: "What cures me is what infects or affects me; what allows me to live causes me to age prematurely. My heart is twenty years younger than I am, and the rest of my body (at least) a dozen years older...I am no longer my own age." For Nancy, time – the primary condition of our experience of the world – morphed such that instinctive ways of negotiating his life and interpreting his life ceased to be reliable.

L'Intrus connotes a combatant, an enemy, or an invasion in the transplant, and in Nancy's experience, the heart transplant functions simultaneously as an adversary and an ally, dividing his body and his identity along precarious fault lines:

> *The intrus exposes me, excessively. It extrudes, it exports, it expropriates: I am the illness and the medical intervention, I am the cancerous cell and the grafted organ, I am the immuno-depressive agents and their palliatives, I am the bits of wire that hold together my sternum...I am becoming like a science fiction android, or the living-dead...*

These observations amount to a picture of a medical operation that resulted in a full destabilization of the self. While few heart transplant recipients wield the philosophical insight and rhetorical power of Nancy to articulate their experiences, the evidence suggests that many share his distress over the impact of the procedure and the inadequacy of their doctors' explanations. The incongruity between prevailing medical views about the meaning of the body and many patients' actual experiences of heart transplantation is more than a mere academic curiosity. It could potentially affect the outcomes of these patients.

It is interesting to note that while transplant patients are encouraged to think about their organs as "spare-parts," large-scale campaigns promote organ donation by employing gift metaphors and appealing to beliefs about the deceased donor "living on" in recipients.[12,18] Furthermore, as pointed out by various anthropologists including Leslie Sharp, lay persons' intuitions about the body that are at odds with medical models are exploited for the purposes of public awareness, resulting in contradictions within the medical institution itself."[9]

A Phenomenological Approach to Heart Transplantation

The phenomenological view is not a panacea: it will not, on its own, cure the distress that many transplant recipients experience, nor can it prevent any unwanted outcomes of the procedure. But, in contrast to the biomedical model, it offers the possibility of greater insight into life with a grafted heart, improved communication between physicians and patients, and the philosophical versatility to learn from emerging medical knowledge that challenges accepted norms. As Nancy eloquently remarks: "the debate I saw unfolding, between those who consider [heart transplantation] to be a metaphysical adventure and those who would see it as a technical performance, is vain: it is a matter of both, one in the other."[17] The doctors who perform heart transplants and care for recipients could benefit from widening their approach to include the less "technical" implications of their work. Of course there is already recognition that something more is at stake: as cultural anthropologists remind us, medical institutions use "metaphysical" themes to their benefit in public awareness campaigns, even while denying them in other contexts. The task, then, is to

question the biomechanical model of the body that carries so much currency among health care practitioners and begin to see the body from the perspective of the individual patient – not as a *Körper*, but as a *Leib*.

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References

1. Marcum J. Biomechanical and phenomenological models of the body, the meaning of illness and the quality of care. Med Health Care Philos. 2004;7(3):311-20.
2. Brenner A. Leib statt Körper. Studia Philosophica: Jahrbuch der Schweizerischen Philosophischen Gesellschaft. 2003;62:47-59.
3. Flynn B. Zalta E, editor. Maurice Merleau-Ponty [homepage on the Internet]. Stanford: Stanford University; c2006. [updated 2004 Jun 14]. The Stanford Encyclopedia of Philosophy; [about 22 screens]. Available from: http://plato.stanford.edu/archives/sum2004/entries/merleau-ponty/
4. Merleau-Ponty M. Phenomenology of Perception. Smith C, translator. London: Routledge; 1989.
5. Taylor DO, Edwards LB, Boucek MM, Truolock EP, Waltz DA, Keck BM et al. Registry of the International Society for Heart and Lung Transplantation: Twenty-third Official Adult Heart Transplantation Report - 2006. J Heart Lung Tranplant. 2006 Aug;25(8):869-79.
6. Dew MA, Myaskovsky L, Switzer GE, DiMartini AF, Schulberg HC, Kormos RL. Profiles and predictors of the course of psychological distress across four years after heart transplantation. Psychol Med. 2005 Aug; 35(8):1215-27.
7. Rivard AL, Hellmich C, Sampson B, Bianco RW, Crow SJ, Miller LW. Preoperative predictors for postoperative problems in heart transplantation: psychiatric and psychosocial considerations. Prog Transplant. 2005 Sept;15(3):276-82.
8. Kaba E, Thompson DR, Burnard P. Somebody else,s heart inside me: A descriptive study of psychological problems after a heart transplantation. Issues Ment Health Nurs. 2005 Jul;25(6):611-25.
9. Sharp L. Organ transplantation as a transformative experience: anthropological insights into the restructuring of the self. Med Anthropol Q. 1995 Sept;9(3):357-89.
10. Lock M. Transcending mortality: organ transplants and the practice of contradictions. Med Anthropol Q. 1995 Sep;9(3):390-3.
11. Haddow G. The phenomenology of death, embodiment and organ transplantation. Sociol Health Illn. 2005 Jan;27(1):92-113.
12. Joralemon D. Organ wars: The battle for body parts. Med Anthropol Q. 1995 Sept;9(3):335-56.
13. Inspector Y, Kutz I, David D. Another person,s heart: Magical and rational thinking in the psychological adaptation to heart transplantation. Isr J Psychiatry Relat Sci. 2004;41(3):161-73.
14. Bunzel B, Schmidl-Mohl B, Grundbock A, Wollenek G. Does changing the heart mean changing personality? A retrospective inquiry on 47 heart transplant patients. Qual Life Res. 1992 Aug;1(4):251-56.
15. Potts M. Morals, metaphysics, and heart transplantation: Reflections on Richard Selzer,s ŒWhither Thou Goest., Perspect Biol Med. 1998;41(2):212-25.
16. Sylvia C, Novak W. A Change of Heart. New York: Warner Books; 1997.
17. Nancy J-L. L,Intrus. Trans. Susan Hanson. Paris: Galilee, 2000.
18. Youngner SJ, Fox RC, O,Connell LJ, editors. Organ Transplantation: Meanings and Realities. Madison: University of Wisconsin Press; 1996.