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Carleton University

**Seeking to Cure by Replacement:
The Political Economy of Organ Transplantation**

A thesis submitted to the
Faculty of Graduate Studies and Research
in partial fulfilment of
the requirements for the degree of
Master of Arts

Institute of Political Economy

by
Lindsey McKay

Ottawa, Ontario

January 2001
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acceptance of the thesis

**Seeking to Cure by Replacement:
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Submitted by Lindsey McKay in partial fulfilment of the requirements
for the degree of Master of Arts

Thesis Supervisor

Director, Institute of Political Economy

Carleton University
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Abstract

When the ‘truth’ that ‘brain death’ is death was questioned in 1999 at the House of Commons, it was refuted and dismissed. This thesis asks how it was possible to marginalize a challenge to the central premise of organ transplantation - that organs are removed from the dead? It is argued that treatment by replacement has been accomplished and is currently governed by a ‘transplant episteme’. The history of this therapeutic modality in the West and specifically within Canada is traced using analytical tools from Michel Foucault and Bruno Latour. It is shown that truth claims based on scientific legitimacy and morality underlie the creation of ‘chimeric’ and ‘natural resource’ bodies. In this way a ‘discourse of donation’ ‘black boxes’ questions regarding this way of seeking to cure and the donor’s death. The consequence to public debate is to render intolerable any concerns that raise the possibility of wrongdoing.

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To the peaceful resolution of ontological crises.

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Introduction

Every few months a story about organ donation appears in a Canadian newspaper. In the last few years the message of these stories is that our identity as kind people, interested in the good of the whole, appears to be in question. Compared to other developed countries, Canada has a low organ donation rate. We are told that the failure of our society to service the needy is causing people waiting for organs to die. In response to media attention, the efforts of lobby groups and the Official Opposition to bring this problem to the government's attention, it was decided in the fall of 1998 that the House of Commons Standing Committee on Health would convene a study of "The State of Organ and Tissue Donation in Canada." By holding a public forum whereby witnesses were called upon to inform federal Members of Parliament, the problem of organ supply reached national political attention.

During fourteen days of hearings, virtually every witness and all legislators deplored the lack of available organs. Newspaper articles announced "Organ shortage at 'crisis' level," with graphs displaying "those damning statistics" of Canada's "shamefully" low "organ donor rate," among the worst in the Western world.¹ Top stories with photos of young parents with babies told the country that precious lives remain "in search of the gift of life" while others die waiting.² Everyone agreed to the 'truth' that not enough organs are being donated. The identified problem is that the supply of organs does not match the demand.³ To ameliorate the "supply crisis," disease foundation

¹ Derek McNaughton, "Organ shortage at 'crisis' level: Health official says shortage is severe, getting worse." *The Ottawa Citizen* Wednesday, February 3, 1999, p. A4. Anne McIlroy, "The double agony of waiting for organ transplants; Death watch: Nobody wants to think about it, but donating a loved one's heart, liver or lungs can save a life." *The Globe and Mail* Saturday, April 24, 1999, p. A7. Editorial "Canadians lag in organ donations: Here are some simple steps that would help us to do better" *The Globe and Mail* Saturday, July 16, 1998, p. D6.

² Derek McNaughton, "In search of the gift of life: Parents ask MPs for organ donor registry" *The Ottawa Citizen* Wednesday, February 10, 1999, p. A3. Anne McIlroy, "Family stories give crisis a human face: In sombre day of testimony, grieving relatives implore MPs to improve organ-donation process." *The Globe and Mail* Wednesday, February 10, 1999, p. A14.

³ Editorial "Organ donations: Solutions, solutions: We can both encourage generosity, and develop xenotransplants" *The Globe and Mail* Monday, March 8, 1999. Mark Kennedy, "MPs urge national program to track organ donations: Canadian rate of giving among worst in the western world" *The Ottawa Citizen* April 15, 1999, p. A1. Mark Kennedy, "B.C. official presses for organ donor plan" *The Ottawa Citizen* Friday, March 12, 1999.

representatives, transplant surgeons and organ procurement organization spokespersons called for government action to centralize control over the 'donation system' to maximize harvesting. Concluding the study, the final report by Members of Parliament endorsed the idea of a Canadian Transplant Network to register more citizens as 'intended donors' and intensify regulations governing hospitals to improve identification of 'potential donors' and improve asking techniques to secure consent to more 'actual donors'.

The problematization of "organs and tissues" in contemporary Canadian society is not at all odd. What stands out - for those paying close attention to this event - is the attempted objection by a small number of dissenters to the use of 'brain dead' patients as a source of organs. One day, in the middle of the hearings, three doctors testified that transplant donors are not dead. Newspaper headlines announced the next day: "Brain dead donors 'alive'."⁴ It is reasonable to expect that this dissent, which throws the whole enterprise into question, would cause considerable debate. Instead, the assertion of a counter-truth - called "an unfortunate distraction from the real issues" by transplant advocates - was kept to no more than a skip of the record. Legislators, medical experts, a rabbi and bioethicists repudiated the claim that patients were alive or could survive 'brain death'. By re-asserting and reinforcing the 'truth,' they dismissed the attempt to raise fundamental questions about the ethics of transplantation and continued debate on how to alleviate the organ shortage. It is clear from this incident that the strength of consensus supporting this therapeutic modality rendered questioning 'organ donation' intolerable. Recognizing this event as a breaching moment, the question that guides this thesis is: how was it possible to marginalize a challenge to a central premise of transplantation - that organs are removed from persons who are dead ?

Answering this question requires an account of how the 'donation' of "organs and tissues" has come to be a contemporary problematic of government and a political issue in Canada in the late 1990s. The argument made in this thesis is that transplantation, as practised in Canada (and the United States) at this particular juncture, is governed by a dominant paradigm of truth I call the transplant episteme. The social order brought about

⁴ Mark Kennedy, "Brain dead donors 'alive': MDs debate ethics of transplants" *The Ottawa Citizen* Wednesday, March 3, 1999. Anne McIlroy, "From one who's been there: Don't alter organ-donation law: Health committee hears testimony of dangers of early 'harvesting'" *The Globe and Mail* Wednesday, March 3, 1999, p. A2.

over the last thirty years to treat a small but significant segment of society by replacing their organs proceeds on the basis of an orthodoxy that forecloses the possibility of wrongdoing. This is particularly the case now that the voluntary “express consent model” is presented as the more ethical “Canadian approach” to obtaining organs in comparison to the financial incentives now being asserted as necessary and introduced in the United States.⁵ It was not new means of obtaining organs that the dissenters questioned but the basis upon which organs have been removed from donors for four decades.

What allowed legislators to dismiss a challenge to a central premise of transplantation was not the epistemic superiority of medical science experts able to provide ‘the truth’ but the strength of the network upholding this way of doing things. Clearly, the absence of a lay constituency for dissenters to draw upon compared to the sixty-seven organizations and institutions witnesses represented on the other side contributed to the ease with which their counter-truth could be dismissed. ‘Brain death’ is death because it has to be in order for ‘organ donation’ to proceed. How this confrontation was conducted and turned out requires weighing the allies and resources marshalled on either side of the debate.⁶ To this end, this thesis analyses the transplant episteme and the challenge to it in 1999 through a tracing of the transformations organ transplantation underwent in the process of developing into a way of seeking to cure perceived and presented as an unmitigated good. This falls into three parts: how the transfer of body parts became a therapeutic technique, how the ‘brain dead’ came to be used as a source of organs and how transplantation came to be known as ‘organ donation’. Aligned into legitimating and justificatory forms of power, this historical detail is used to demonstrate how it was possible for transplantation to withstand a fundamental challenge at the House of Commons event. On account of the episteme, the outcome of this breaching moment protected transplantation from any recognition of limits that would prevent it from continuing. Before turning to the argument presented in this thesis what

⁵ The report produced by the Standing Committee on Health from this study in April, 1999 is entitled, “Organ and Tissue Donation and Transplantation: A Canadian Approach.”

⁶ This research method is also used for the case of resistance to a diagnostic technique for child sexual abuse at a public forum in Britain in Alan Collins, Gavin Kendall and Mike Michael “Resisting a diagnostic technique: the case of reflex anal dilatation” *Sociology of Health and Illness* 20(1): 1-28, 1998.

follows is an account of where this work is situated within academic research and a detailed outline of the research strategy employed.⁷

Context and Contribution of the Research

Neither of the two sets of critical literature relevant to this topic can satisfactorily account for the confrontation and outcome of truth claims at this event. In the field of organ transplantation, ethnographic research by medical anthropologists exposes ideological disjuncture around self/body inviolability created by crossing self/other and life/death boundaries. As these authors point out, this research area has yet to fully investigate the means by which culturally infused forms of power operate to produce the dominant knowledge that holds transplantation in place.⁸ The question posed in this literature is often how people make sense of transplantation (sometimes sharing with mainstream literature a focus on the recipient, and a view of 'brain death' and the "express consent model" as unproblematic) rather than why and how this has become the way we do things. A need to examine the latter is particularly acute in light of the knowledge that transplantation is not practised elsewhere and the way it has become reality in Canada renders out-of-range critiques that could lead to other possibilities. A notable exception is Margaret Lock's comparative research on the acceptance of 'brain death' in North America compared to its refusal in Japan. Her findings are therefore drawn on and built upon in this thesis. Still, the role of science and public acceptance of a diagnosis for death tells only one part of the story important to the 1999 Event. What enabled sixty-seven organizations to be part of the "consensus" that "organ and tissue donation" is a priority is the other part that also requires attention.⁹ This literature has yet to account for how 'organ donation' became a cause pursued by volunteers and the 'donation process' a standard medical procedure.

⁷ I am referring here not only to sociology of the body but also feminist research covering a wide range of topics all of which address ways in which women in their bodies are socially constructed and medically altered.

⁸ See B.A. Koenig and L.F. Hogle "Organ Transplantation (Re)Examined?" *Medical Anthropology Quarterly* 9(3): 393-397, 1995.

⁹ See chapter five, page 134.

At a theoretical level, medical anthropologists and academics from a range of fields identify the Cartesian legacy of mind/body dualism as the source of a biomedical fragmentation of the body. This is considered to be a form of power important to modern subjectivity. It is more common, however, to find attributions of phenomena to "the triumph of the Cartesian view," than examinations of whether this split is a *fait accompli* or currently underway and if so how that is being accomplished. The detachment of this work from analyses of power that investigate distinctions made between people *vis-a-vis* differential treatment leaves the impression of a generalized, neutral phenomenon underway.¹⁰ Therapeutic techniques such as transplantation (which can be used for genetic engineering and new reproductive technologies) have therefore not come under scrutiny in relation to Cartesianism. This literature thus has little to offer in terms of accounting for how the body is fragmented, particularly as it establishes some truth-claims as more powerful than others.

The contribution of this thesis is an empirical account of how the therapeutic use of the body has been and continues to be accomplished by the transplant episteme. It is both theoretical and practical in linking a historical account of how we have come to treat patients differently based on death order to the formulation of public policy at the House of Commons event in the present. Understanding what happened in 1999 requires a broad view that can account for the positive knowledge that the vast majority were engaged in and how this reality came to be so true it could not be questioned. This is done through the conceptualization of a transplant episteme as a configuration of power inscribed in a language that enables the formation of two kinds of bodies: the 'chimera' and the 'natural resource', known as the 'recipient' and 'donor'. Through the layering of a visible 'social' over an invisible 'scientific' process of fact-production, personhood is abstracted from embodiment to make possible these two kinds of bodies. Greater attention is given here to the division and re-building of the 'natural resource' body/person through the specific

¹⁰ Paul Rabinow, for example, argues that "in-and-of itself, this shift away from an organismic focus is neither good nor bad." Underlying the neutral stance taken in with respect to fragmentation of the body (other than by theologians who considered it dehumanizing) is a commitment to the liberation attributed to the shift away from traditional views of 'nature' *vis-a-vis* the body. Claims from biomedical discourse (for example, brain development) have been used by both left and right in political battles over rights and public policy. Paul Rabinow "Severing the Ties: Fragmentation and Dignity in Late Modernity" *Knowledge and Society: The Anthropology of Science and Technology* vol 9: 169-187. 1992. p. 185.

identification of the 'potential donor' and 'brain death'. By 1999 traces of human agency that brought this reality into existence are erased. The social order left in place contains the creation of demand and the donor's death within 'black boxes' to structure what is questionable upon the unproblematic. This truth, of the transplant episteme, that couples a legitimating scientific form of knowing with a justificatory social structure of power, is so strong by 1999 that it renders the possibility of another reality out-of-range. To make this argument, this thesis draws on the traditions of Michel Foucault and Bruno Latour, as used in the work of Nikolas Rose, Ian Hacking and Steven Ward. This set of authors provide theoretical accounts of truth, knowledge and reality in the West that allow for an examination of the conditions of possibility and transformative actions that moved transplantation from a fragile idea to the status of unquestionable.

Chapter Outline

Chapter one presents and accounts for the analytical tools used to examine the configuration of power constitutive of the transplant episteme and the 1999 House of Commons event. Nikolas Rose's Foucauldian approach is compared to actor-network theory (ANT) as the two lenses found to be most useful to the case of transplantation. The argument made in the chapter is why and how the latter is added to the former as the theoretical framework to be applied throughout the thesis. Nikolas Rose's lines of enquiry provide a framework to investigate the different political forces, forms of knowledge, expertise and domains of intervention that gave rise to this therapeutic technique. It is shown how the use of actor-network theory within each of Rose's categories connects the abstract more concretely to agents, institutions, professions, hospitals and legislatures where practices and people do the work of creating the chimeric and natural resource bodies. Combined, this theoretical lens enables the empirical findings to be seen in terms of Foucault's ideas of the structuring of thought, governmentality and biopower as well Bruno Latour's location of science in Western epistemology and ANT's theory of translation and alignment. Primary and secondary sources are then analyzed using this theoretical lens and the research method of discourse analysis to build the arguments of the substantive chapters.

Using one of Nikolas Rose's lines of enquiry, chapter two addresses the formation of transplantation as a *technology of health*. The argument made in this chapter is that this way of seeking to cure people was not inevitable but emerged out of a particular combination of forces. The movement from accessing the dead for knowledge, to transferring parts between live bodies for therapy, to replacing dying organs from the 'living dead' is followed to analyze the vested interests that propel transplantation as an industry.¹¹ It also allows for an account of the shift in medical gaze from seeing the unique individual subject to seeing the 'sameness' of the body as an object of use to others in parts. This leads to an account of the chimeric body as a hybrid that contains two different genetic entities. This chapter shows the human agency involved in creating a particular therapeutic modality where others could exist which is a dimension of controversy regarding the "recipient" 'black boxed' in the discourse of donation into an ability or inability to transplant.

Creating the chimeric body as a way to prolong/save lives requires the creation of a natural resource body to serve as the source of "spare parts". To replace organs other than kidneys, a human source was established from the dying through the construction of the "cadaver donor." Chapters three and four address how the use of the 'living dead' as a source of organs was legitimated and justified. The processes by which initial practices are translated into strong truths is followed over the last quarter century using the world's first heart transplant in 1968 as a turning point. Two developments emerged from this: a less visible process of fact construction with the medical profession and a public process of giving meaning to transplantation through a discourse of donation that established body parts as "gifts."

Chapter three addresses how it came to be considered legitimate to medically intervene in the bodies of some dying patients not for the sake of saving their life but that of another. The argument made is that disagreement over when organs could be procured was 'black boxed' by making a stage of disintegration in the process of dying a visible category of 'non-person.' A weak and fragile idea in the late 1960s, hotly debated among

¹¹ Barbara Koenig and Linda Hogle identify "a political economy interpretation of the vested interests that propel the transplantation industry" as one of four items that require further research within medical anthropology literature on organ transplantation. This thesis (and chapters two and four in particular) takes up this task. See B.A. Koenig and L.F. Hogle, 1995. *op.cit.*

surgeons, the 'living dead' as "dead" transformed into fact through the continual release and refinement of a diagnosis for 'brain death.' By establishing certain patients as legitimate objects, this type of death serves as an 'obligatory passage point' that must be agreed to in order for this therapeutic modality to proceed. While not the case elsewhere, in the West 'brain death' came to be accepted through scientific methods of legitimation. As a consequence, it became possible to detach the end of personhood from the cessation of the body, separating personal life from biological existence.

Paradoxically, it is the extension of the wishes of an abstract personhood that is used to realize the natural resource body. Chapter four uses Rose's *strategic* and *assemblage* lines of enquiry to examine how what I call the discourse of donation functions as a visible form of power that sustains the expansion and re-ordering of hospital-based medical practice. It is argued here that this discourse provides an economy of representation of giving rather than taking to induce participation in transplantation on moral grounds as a justificatory mechanism. A common knowledge of transplantation, through the conceptualization of 'the body' as a 'gift' and the language of 'donors' and 'recipients', presents donation as a desirable moral act. The secular ethical regime formed on this basis accounts for the cultivation of attitudes and practices conducive to this *technology of health*, specifically through the enrolment of resources and allies and routinization of medical procedures to remove and replace body parts which intensified during the period of 1984 to 1999. The problematic around why more donation does not occur is also examined here as a phenomenon that "builds the questionable upon the unproblematic."¹² In these ways, the 'black boxes' of the episteme are kept in place.

The arguments made in these chapters situate the analysis presented in chapter five using primary data taken from the 1999 House of Commons Standing Committee on Health study on "The State of Organ and Tissue Donation in Canada." Through the lens of the transplant episteme, it is possible to see that what makes the dissent in 1999 a breaching moment is the exposure of the legitimating and justificatory forms of power linked over thirty years. The discourse of donation required a legitimating rhetorical strategy to defend itself against the claim that the use of patients as a source of organs

¹² Stephan Fuchs *The Professional Quest for Truth: A Social Theory of Science and Knowledge* Albany: State University of New York, 1992. p. 222 footnote 2.

kills them. To this end, dominant voices of authority acted according to Bruno Latour's idea of a 'Great Divide' between 'science' and 'social' to dismiss and deconstruct dissenters' counter-truth by continually returning the question of the donor's death to one of accuracy. 'Brain death' could not be considered other than as a present or absent 'black box'. As in other instances where medical/scientific discourse is used as the final arbitrator of personhood, what gave these truth-claims a power strong enough to marginalize dissent was the justificatory force of allies and resources lining up in support.¹³ It was the sheer weight of investment in the transplant episteme as one way of seeking to cure that led to the 'win' for those who argued that 'brain death' is death.

¹³ See M. Jean Heriot "Fetal Rights versus the Female Body: Contested Domains" *Medical Anthropology Quarterly* 10(2): 176-194.

Chapter One Analytical Tools

Certainly, one of the West's particularities is to be found in the tension between the body, as a mere thing carried by a triumphant science and technology, and the still present sense that the body and its parts are always more than things.¹⁴

An analysis of organ transplantation requires a theoretical lens capable of accounting for the creation of the organ as a living, quasi-object that is transferred through a non-monetary economy within specific geographic spaces. Theories of capitalism, theories of the state in relation to the market economy as well as theories of class, race and gender relations were found not irrelevant but inapplicable to the case of non-commodity exchange. As this thesis shall demonstrate, theories of gift exchange were also rejected on the grounds that organs are not true objects and for this reason cannot be part of reciprocal exchange relations. Analyzing the way in which a particular therapeutic modality has led to the creation of a body parts as quasi-objects required an account of medicine and truth production. The work of Nikolas Rose and Bruno Latour were found to be useful to this task.

A useful methodological strategy to account for the transplant episteme thus combines a Foucauldian inspired analytical framework for medicine by Nikolas Rose with actor-network theory (ANT) from sociology of knowledge. Empirical data drawn from primary and secondary sources listed in Appendix C are interpreted through this lens using discourse analysis in the chapters that follow. Rose's 'history of the present' research method provides various lines of enquiry to map the configuration of power attendant to transplantation, as a specific therapeutic technique. To this I add actor-network theorists' principles of investigation and idea of alignment through networks to detail the creation and strength of the transplant episteme. The latter allows for an understanding of the resources that had to be in place for marginalization of dissent to be possible.

¹⁴ Paul Rabinow, 1992 *op.cit.* p. 185.

Nikolas Rose and actor-network theorists share a concern with knowledge, power and truth. Of critical importance, both perspectives shed the normative stance of medicine and science that truth is "out there" waiting discovery. Instead, both theoretical perspectives view reality as established through the heterogeneous coming together of processes, techniques, sites and practices that could have remained separate. This draws attention to the contingency in all that is taken for granted as "natural," "normal" or unproblematic 'fact'. Realist epistemology is refuted through the claim that truth is no more than a "temporary expression of knowledge/power."¹⁵ Rose illustrates this by adopting Foucault's genealogical method locating "deep structures" and "discontinuities" of the present within the context of long-term historical change in the West. By drawing attention to the conditions in which reality arose, what is currently accepted as 'truth' is seen as a product of specific relations. Actor-network theorists accomplish the same effect through different means. In their view, truth has more in common with cable T.V. than traditional epistemology. "A statement must plug in others in order to become true. Conversely, one must be plugged-in to be a part of the network of the truthful."¹⁶ Micro-sociological research leads them to uncover the resources and allies constructed, aligned and drawn on to create the present. Identifying each part and accounting for its mobilization into a network illustrates the uncertainty inherent in a reality made up of many parts. To Rose's abstract identification of "what came to light" is ANT's meticulous tracking of facts "in the making."

Rose's Foucauldian research method helps us to understand how a 'transplant episteme' is possible and the configuration of power contained therein. It is weak, however, in accounting for the concrete creation of 'truth' including the concomitant resolution of contest. It is difficult to gage how strong or weak a particular 'truth' is through Foucault's conceptualization of power. ANT addresses these shortcomings by providing the conceptual tools to examine the details of the case. Only through "empirical excavation" can one uncover how stability and contestation arise, are

¹⁵ David Armstrong "Bodies of Knowledge/Knowledge of Bodies" *Reassessing Foucault: Power, Medicine and the Body* Colin Jones and Roy Porter (eds.) London: Routledge, 1994. p. 17.

¹⁶ Steven Ward "Filling the World with Self-Esteem: A Social History of Truth-Making". *Canadian Journal of Sociology* Vol. 21, 1996. p. 6

conducted, and turn out.¹⁷ This argument will be demonstrated through an analysis of Rose's 'history of the present' research method and the techniques of truth making of actor-network theory. I conclude this chapter by showing how these two approaches fit together to provide an appropriate theoretical framework and form of empirical investigation to analyze the transplant episteme.

1.1 A Foucauldian Approach to the 'History of the Present'

Nikolas Rose is one of many theorists interested in the types of analysis opened up by the work of Michel Foucault. Governmentality and medicine are the two areas of Foucault's writing that Rose has used to analyze advanced liberal democratic societies and the role of psychology to the concept of personhood.¹⁸ To advance work of this nature Rose offers guideposts to 'historians of the present' seeking to pursue the concerns and philosophical orientation of Foucault's thinking.¹⁹

This approach differs from attempts to show cultural influences on "universal" science and medicine by taking a much more encompassing view of the role played by medicine. Rose explains that Foucault saw medicine as 'bound up,' since the end of the eighteenth century, with the ways in which the very idea of society "has been brought into existence and acquired a density and a form."²⁰ Medical reason and political reason forged into one as the modern state took on the task of administering life.²¹ It is the form that power takes and its affect that is the subject of investigation.

In *Birth of the Clinic* and *History of Sexuality* Foucault probed the connection between knowledges respecting large populations and practices respecting individual bodies.²² Medicine contributed to the formation of individualism as one of the "central

¹⁷ Alan Collins, Gavin Kendall and Mike Michael, 1998. *op.cit.* p. 5.

¹⁸ See Peter Miller and Nikolas Rose "Governing Economic Life" *Economy and Society* 19(1): 1-31, 1990. and Nikolas Rose *Inventing our selves: Psychology, power, and personhood* Cambridge: Cambridge University Press, 1996.

¹⁹ Nikolas Rose "Medicine, History and the Present" *Reassessing Foucault: Power, Medicine and the Body* Colin Jones and Roy Porter (eds) London: Routledge, 1994.

²⁰ Rose, 1994. *op.cit.* p. 54.

²¹ *Ibid.* p. 54.

²² *Ibid.* p. 48.

coordinates that have defined our contemporary experience of ourselves, and the present which we inhabit.”²³

Medicine was bound up with the delineation of the unique human being, the human person in his or her very individuality and vitality, as a possible object for *positive knowledge*; that is to say, as a territory which could be mastered by a form of truth regulated by rationalities proper to the codes of scientific reason.²⁴

Many studies using a Foucauldian perspective have sought to identify aspects of the way in which individuals are governed. This thesis will show how transplantation, as a more recent medical practice, governs individuals by bringing about the reverse: generic-ness as a territory to be mastered. The emergence of replacement as a treatment technique reveals that in identifying the uniqueness of persons, what has also become visible are groupings of “compatible” persons classified into “types.” Concurrently, human ‘life’ is no longer the whole but the distinct, semi-transferable, quasi-independent parts that in combination comprise persons. Transplantation re-orientes the medical gaze from a singular to a ‘double gaze’ by positioning patients as *subjects and objects* of medical intervention; seeking treatment as well as providing the material needed to treat others. Maintaining one life using this technology entails subverting the singularity of the subject through the making of hybrids. “Matching” bodies positions persons as the subject to be cured and the source of cure.

Foucault identified the institution of the clinic as critical to bringing together the various forms of knowledge, techniques and practices that gave rise to the individual. I will show how an element that “opened a clearing” through which transplantation could begin was also an institution: the large hospital where the bodies of persons dying by contrary order are brought together. Taking this treatment technique as the centerpiece of my analysis, all other lines of enquiry can be seen as practices that flow from and further enable transplantation.

It is not the technique itself that is a problem in 1999 but the medical supplies needed to fuel it. Following Foucault’s style of enquiry, it is the emergence of “organ supply” as a problem “identified and construed as in need of amelioration,” that requires

²³ *Ibid.* p. 49.

²⁴ *Ibid.*

investigation.²⁵ Why has this come to assume political salience? And how have disparate components come together to form this troubling dimension of Canadian society? To answer these questions, the first task of Rose's research method is to "trace out, from the point of view of the problem that concerns one today, the diverse connections and liaisons that have brought it into existence and given it its saliency and its characteristics."²⁶ To do this, he suggests an act of decomposition along five lines of enquiry: *technology of health, expertise, dividing practices, strategic* and *assemblage*. In examining the contribution of each to the problems of the present, the researcher must abide by two methodological rules. First, one must attend to the diversity and heterogeneity in the values, interventions, language and events of 'medicine.' This reflects a philosophical stance set against standard accounts of medicine that reduce history to a series of events unfolding along a linear, universal pathway towards progress.²⁷ Second, the distinction between a realm of reason and a realm of power must be refused.²⁸ Theories of disease causality cannot be separated from sites of intervention. Discourses of medicine are similarly tied to the structuring of space, fused to the technologies of diagnosis and positions of medical personage. To capture Foucault's concern with epistemology and discourse, historical research "is a matter of the meticulous investigation of the varied and complex ways in which practices of truth situate persons in particular relations of force."²⁹

Producing the "organ supply" problem, Rose identifies *technologies of health* as the "technical forms within which one seeks to enact the business of curing sickness or producing health."³⁰ Understanding how this treatment modality emerged, the adjustments it has led to and the relations empowered by it, as they have unfolded from 1960 to 1999, render an analysis of current transplantation practice possible. Located within this analytical category is attention to relations between subjects distinct to a particular technology. Medical personages are empowered, for example, to convert patients from *subjects* to *objects* as a responsibility attendant to curing the ill through

²⁵ Miller and Rose, 1990. *op.cit.* p. 3.

²⁶ Rose, 1994. *op.cit.* p. 53.

²⁷ *Ibid.* p. 49.

²⁸ *Ibid.* p. 52.

²⁹ *Ibid.* p. 53.

body part replacement. Significant as well is the way in which decisions and actions made about patients' problems differ according to the presence and predominance of various *technologies of health*. I argue that for transplantation, the emergence of new kinds of patients – 'potential donors' waiting to "give" and 'potential recipients' waiting to "receive" – converts one person into a 'natural resource' object available for procurement and the other into a chimera of the two.

Various types of *expertise* shape the contemporary deployment of medicine. This category requires an examination of "the involvement, at different times and around different persons and populations" of different types of personnel in terms of rivalries, divisions of labour and forms of legitimacy.³¹ Experts enact *dividing practices* to separate certain kinds of patients, phenomenon or methods of enquiry as distinct from others. Under this line of enquiry, Rose instructs:

...A description of the configurations of processes within which persons and populations were produced as objects of medical attention, and were separated from those which would be the focus of other authorities and apparatuses - religion, law, education.³²

In the case of transplantation, it is medical experts who have come to oversee death as the sole authority charged with determining its presence. Dominant Western religions retain a position of authority in matters concerning the beginning of life but withdrew from the end. Death as an "issue" therefore falls under the category of "science" rather than "philosophy." The determination of death according to this distinction is subject to the legitimating practices of medical experts: measuring, testing and viewing the body. Claims to objectivity, rationality, humanity and truth grounded in realist epistemology and spoken by members of a prestigious profession give credibility to medical persons and practices.³³ In speaking the 'truth', these experts also divide who gives and who receives body parts on the basis of distinctions between patients made through new classifications. As instructed, this thesis will demonstrate the means by which this shift and new categories came into existence and enable this technique for curing illness.

³⁰ *Ibid.* p. 52.

³¹ *Ibid.* p. 51.

³² Rose, 1994. *op.cit.* p. 51.

³³ Collins, Kendall and Michael, 1998. *op.cit.* p. 16.

The fourth analytical division is what Rose calls *strategic*. This term identifies the “ways in which medical thought and medical activity have sought to realize themselves.”³⁴ Examples range from campaigns of social hygiene, inoculation or the “social marketing” of lifestyle modification to medical inspections, medical institution reform and the staffing of the population with medical officers of health.³⁵ Medicine is a matter of the means by which citizens become active participants in its practice on them “simultaneously *subjected* to the medical gaze but also in some measure self-directing.”³⁶ This category allows for an analysis of how citizens are mobilized to participate in transplantation, particularly as “givers” of organs.

Closely affiliated with the activities through which medicine realizes itself are the spatial arrangements of *assemblages*. The combination of “spaces, persons, techniques within which medicine has been deployed” brings together the objects of attention and areas of problematization.³⁷ Since the beginning of the nineteenth century, five great “*dispositifs*” have organized medical activity: a medico-administrative apparatus for regulating social space, the home and family for hygiene, staffing the population with medical agents, and clinical and curative hospitals. Each “apparatus” entails a specific space for regulation tied to a range of activities.

Rose’s framework is useful to the argument of this thesis by offering a set of sites and practices within which the transplant episteme is constituted. Power is a product of knowledge, formed through the emergence of medical practice based on scientific legitimation and moral justification. Perception of death is altered by the presence of transplant medicine structuring the visible to the invisible differently than previous medical practice. Drawing attention to the everyday activities of a wide range of actors places emphasis on how knowledge is formed and the effect it takes in shaping society. Each line of enquiry does not, however, stand side-by-side in equal contribution to the transplant episteme. I conceptualize the formation of power within three groupings of these categories (*technology of health*; *expertise and dividing practices*; *strategic and assemblage*) and as they fit together using actor-network theory’s idea of network

³⁴ *Ibid.* p. 52.

³⁵ *Ibid.*

³⁶ *Ibid.* p. 48.

³⁷ *Ibid.* p. 51.

translation. Hence, as elements of the episteme, *dividing practices* and the *technology of health* of transplantation form 'black boxes' upon which the visible dimensions that Rose calls *strategic* (and partially visible *assemblages*) stand.

1.2 Sociology of Knowledge: Actor-Network Theory

An episteme in the eyes of actor-network theory is a strong 'associational network.' If Foucault (through Rose) contributes an ability to perceive epistemological shifts through the 'shedding of light' across and into different planes, actor-network theory accounts for the construction of the window. The former is broad, abstract and focused on what becomes visible. By documenting the ways in which 'facts' become established as 'truth,' the latter is linear and dynamic; concerned more with process than effect. Both emphasize the social conditions and combination of forces that converge to produce a particular Reality but see it in different ways. This is clear in their differential treatment of contingency as the element that holds out the perpetual possibility of change. For Foucault, the present is contingent upon the ways in which disparate entities come together and interact at a particular juncture. For actor-network theory, contingency lies in identifying how all the links that make a chain are joined. This knowledge presents stability as only as strong as the weakest link. Contest and its resolution are present in ANT as part of the formation of 'truth'. It is thus useful to supplement Nikolas Rose's conceptual framework with analytical tools from actor-network theory in order to examine how stability is created and contestation resolved in the formation of an episteme.³⁸

A brief detour through the theoretical perspective of Bruno Latour, a key actor-network theorist, is useful to orient an understanding of the methodological strategy employed by this set of authors.³⁹ Their work emerged as a criticism of traditional epistemology relied upon in sociology of knowledge literature. For Latour, science is politics by other means. In place of adopting the cultural practice privileging science as a

³⁸ This thesis does not claim to present all possible illuminations that could have altered the present. Empirical findings are limited by the usual constraint historians confront with respect to the preservation of records.

³⁹ The actor-network theorists I draw from are Bruno Latour, Steven Ward, Stephan Fuchs, Michel Callon

distinct field with special access to truth, he advocates researchers conduct an anthropology of the West.⁴⁰ To view what is going on in this society, the division of knowledge in this tribe separating a 'social' world from a 'scientific' world as "distinct ontological zones" must be abandoned.⁴¹ It is not enough to accept science and look for social influences and biases upon it.⁴² He instructs a principle of symmetry be employed to treat all 'facts' and 'issues' equally: "Do not separate the world as it is from the social representation they provide for it."⁴³

To comprehend dominant Western society, the researcher must look to the 'hybridization' and 'purification' work of science.⁴⁴ The former is the process by which scientists produce 'quasi-objects' or 'quasi-subjects,' simultaneously human, discursive, political, natural, local and global, transcendent and immanent. Purification is the attempt to sanitize hybrids by presenting them as pure objects, pure subjects, etc. Separating experts and debates into 'social issues' and 'scientific questions' is a result of purification work. To step 'outside' this world, is to view all items as integrated and observe the effect of the 'Great Divide' between science and the social. This approach contributes to an understanding of how Western society works.

Latour offers several principles and rules of method to analyze the West. First, one must investigate 'science in the making' rather than 'ready made science'.⁴⁵ This is achieved by either arriving before the facts and machines are 'black boxed' (see below) or following the controversies that re-open them.⁴⁶ Second, the principle of symmetry insists that "we are never confronted with science, technology and society, but with a gamut of weaker and stronger *associations*." The idea that a special scientific method can uncover truth, in the absence of power is 'myth'.⁴⁷ Methodologically, this means that researchers,

and John Law.

⁴⁰ Bruno Latour *We Have Never Been Modern* Cambridge, MA: Harvard University Press. 1993. p.101

⁴¹ *Ibid.* p. 10.

⁴² *Ibid.* p. 21.

⁴³ *Ibid.* p. 10.

⁴⁴ *Ibid.* p. 11.

⁴⁵ Bruno Latour *Science in Action* Milton Keynes: Open University Press. 1987. p. 4.

⁴⁶ *Ibid.* p. 258.

⁴⁷ Hege Bakkan, "The 'Network-Boundness' of Anorexia Nervosa: A Study of Scientific Knowledge Production and the Negotiating Implications of an Actor-Network Approach," Masters Thesis, Carleton University, 1998. p. 19.

Do not look at intrinsic qualities to determine the objectivity or subjectivity of a claim but all the transformations they undergo later in the hands of others. Neither Nature nor Society can be used to explain how and why a controversy has been settled.⁴⁸

Arguing that minds are not separated by the 'Great Divide,' the accusation of irrationality is on principle to be understood as no more than a device used against someone who stands in the way of network formation. The modes of inscription, enrolment and resources mobilized to resolve controversies in the process of 'making science' through network construction is the empirical work to be done. The "history of technoscience is in a large part the history of the resources scattered along networks to accelerate the mobility, faithfulness, combination and cohesion of traces that make action at a distance possible."⁴⁹

Following science "in the making" replaces the question of why with an enquiry into how truth is established. The task is to trace how an initial statement about the world moves from a weak and fragile assertion by specific individuals to an unquestionable 'fact'. Some claims become larger, stronger and more resilient while others are rejected, become false starts or fade away.⁵⁰ Allies and resources are implicated in the crafting and enforcing of 'truth'.⁵¹

Contributing to and building upon the work of Latour, this group of theorists conceptualizes the formation of actor-networks as occurring through a process of 'translation'. This is defined as the process in which "sets of relations between projects, interests, goals, and naturally occurring entities - objects that might otherwise be separate from one another - are proposed and brought into being."⁵² Proponents of an idea enrol allies and enlist resources in support of a statement. Allies that make the statement "'brain death' is death" true, for example, are neurologists, government funding support,

⁴⁸ Latour, 1987. *op.cit.* p. 259.

⁴⁹ *Ibid.*

⁵⁰ Steven Ward, 1996. *op.cit.* p. 6.

⁵¹ Note that ANT does not differentiate between human and non-human "actants." Although both must co-operate, the flattening of distinction between types of agents and animate objects conceals important differences in power that each possessed. For this reason only human allies are considered here with forms of evidence considered under the category resources.

⁵² Michel Callon and John Law, "On the Construction of Sociotechnical Networks" *Knowledge and Society: Studies in the Sociology of Science Past and Present* Vol. 8: 57-83, 1989. p. 58.

organ procurement organizations and organ recipients. Resources drawn upon include hospital protocols, public relations literature, charts, statistics and diagnostic criteria. A moral commitment to cure patients by any means necessary is a value that can be drawn on as a resource to enrol others or quash dissent. As the interests of disparate entities are mobilized into alignment with the statement, they can then be drawn on to further strengthen and extend the network.

Enrolment is achieved through a number of techniques. One is to establish the statement as an “obligatory point of passage” necessary to understand a particular phenomenon. As such, the statement becomes indispensable.⁵³ For example, the ‘fact’ that the donor is dead is insinuated in standard conversations about ‘organ donation’. As actants ‘pass through’ this point, they are drawn into ‘the truth’. To be transformed into certainty, the statement must receive support from and be utilized by a variety of differentially powerful actors, from ‘experts’ to lay people.⁵⁴ Changing work practices to integrate the newly established ‘fact’ is another technique that can secure ‘action at a distance’. As a once fragile statement becomes part of everyday routine practice, it becomes too entrenched to challenge. This kind of dissemination, along with “the careful plaiting of weak ties,” establishes the network as an episteme.⁵⁵

ANT argues that controversies and uncertainties that arise in the formation of actor-networks become closed into ‘black boxes’. Bruno Latour explains,

The word black box is used by cyberneticians whenever a piece of machinery or a set of commands is too complex. In its place they draw a little box about which they need to know nothing but its input and output.... That is, no matter how controversial their history, how complex their inner workings, how large the commercial or academic networks that hold them in place, only their input and output count.⁵⁶

A ‘black boxed’ scientific fact or technical artifact is “what no one is going to dispute.”⁵⁷ Routine use of these ‘facts’ affirms their status as stable, reliable and without risk. Following the principle of symmetry, controversies considered ‘ethical’ or ‘moral’ could

⁵³ Ward, 1996. *op.cit.* p. 6.

⁵⁴ Bakkan, 1998. *op.cit.* p. 21.

⁵⁵ Latour, 1987 as quoted in *Ibid.* p. 20.

⁵⁶ Latour, 1987 *op.cit.* p. 2-3.

⁵⁷ *Ibid.* p. 29.

also be 'resolved' in this way. In medicine, the creation of new classifications through diagnoses, which Ian Hacking has called "making up people," can be interpreted as often involving 'black boxing'.⁵⁸ Attention to the proper application of a diagnosis can deflect from consideration of the rationale, need and legitimacy of the categories of persons created by this knowledge. Collins, Kendall and Michael consider this in relation to a diagnostic technique used to ascertain 'homosexuality' versus 'child sexual abuse.'⁵⁹ For "normal science" or medicine to proceed, "black boxes cannot and should not be reopened."⁶⁰

Textual and non-textual agents are an important feature of fact production; particularly to keep uncertainty or controversy closed. Critical to changing a statement into a fact is the 'deletion of modalities'. Modalities are subject specific identifiers such as time, place, individuals, uncertainty, inconsistencies that make a statement open to refutation on the basis of uniqueness. By removing such references in text or speech by eliminating authors, actors and contextual specifications, a statement appears to be universally applicable. Latour found that textual agents are employed during the establishment of a 'fact' and "when controversies flare up, the literature becomes technical."⁶¹ Non-textual agents that can contribute to "serious speech" include the reputation of 'experts' and institutions. "Awareness of a particular scholar's reputation...helps other researchers in their every-day work to make decisions about whom to listen to, whom to ignore, and whom to trust and enrol in their own work."⁶² Cultural capital is essential as it provides clues for selective attention by listeners. Institutions can serve as a symbolic resource; to challenge a statement made by its representative is to question the authoritative status of the institution itself. Scientists' authority is greatly enhanced by the social position they hold. Surgeons are similarly empowered by societal endorsement, at the extreme referring to them as "God's miracle workers."

⁵⁸ Ian Hacking "Making Up People" *Reconstructing Individualism: Autonomy, Individuality, and the Self in Western Thought* Thomas C. Heller, Morton Sosna, David E. Wellbery (eds.) Stanford: Stanford University Press, 1986.

⁵⁹ Collins, Kendall and Michael, 1998. *op.cit.*

⁶⁰ Latour, 1987 *op.cit.* p. 29.

⁶¹ *Ibid.* p. 21.

⁶² Bakkan, 1998. *op.cit.* p. 26.

Success at each step in the process of network formation contributes to the growing strength of one version of reality. A stable network of truth allows a collectivity to embrace and perpetuate new knowledge. The initial statement, now accepted as fact, is integrated into routine practice to establish group boundaries and ritualize the further establishment of facts.⁶³ Now unquestionable, "the newly established fact may also serve as a moral weapon to be used against transgressors of the group's normative order or to convert the remaining isolated pockets of the group's normative order, conceptual atheists or heathens."⁶⁴ Challenging what was once no more than a fragile assertion becomes more difficult. The ability of representatives of the dominant knowledge to "draw upon more and more powerful material and symbolic resources" than the minority knowledge sets the costs of objecting to the dominant group extremely high.⁶⁵ Entrenchment sets in as the extent to which this 'truth' has already been endorsed and invested in renders the possibility of reversing course out of range. From an organizational perspective, Fuchs argues that "there is too much capital invested in science to successfully challenge it."⁶⁶

Of special relevance to the case this thesis examines is how contest is resolved when networks of different strengths meet. For Nikolas Rose, resistance is endemic to practices of subjectification.⁶⁷ When different practices or regimes meet, conflict, resistance or ambivalence can arise, although none of these is immanent. What happens when such incidents occur is left unexplored. Rose does not deal with battles. Instead, he embraces Foucault's interest in the outcome: what dissection of the corpse led to, for example, rather than the widespread resistance to it and how that was overcome. His project is to uncover what shape and affect shifts in thought take to create different practices of subjectification. However, in the spirit of showing "that things could have been different," I agree with actor-network theory that the resolution of contestation in favour of one network over another is critical to understanding the formation of the

⁶³ Steven Ward, 1996 *op.cit.* p. 7

⁶⁴ *Ibid.*

⁶⁵ Stephan Fuchs, 1992. *op.cit.* p. 14.

⁶⁶ *Ibid.*

⁶⁷ Collins, Kendall and Michael, 1998. *op.cit.* p. 5.

present.⁶⁸ By successfully “deconstructing and reversing the statements of its opponents,” the dismissal of the dissenters’ view that ‘brain death’ is not death at the House of Commons event is interpreted by ANT as a ‘win’ for the transplant episteme.⁶⁹ As Collins, Kendall and Michael argue in the case of child sexual abuse, it is not ‘the truth’ that allowed one group to prevail but the ability to draw on greater resources and allies.

Resistance or constestation arise when what is seen as an unproblematic resource from the perspective of an expert is viewed as a problematic topic from the standpoints of laypersons and other experts. In examining these confrontations we need to unpick the range of allies that could be marshalled on either side.⁷⁰

Taking this approach, what becomes available in weighing up “the costs as well as the benefits of the present we inhabit” is all that the present relies upon to remain true.⁷¹ Dissent at a public forum in 1999 stands as a ‘breaching moment’ in which to view the transplant episteme. My strategy for continuing this inquiry is thus to draw upon the complementary capacity of Rose’s Foucauldian framework and actor-network theory to trace the formation and strength of transplantation as a unquestionable truth of Western reality.

⁶⁸ Rose, 1994 *op.cit.* p. 70.

⁶⁹ Steven Ward, 1996 *op.cit.* p. 6.

⁷⁰ Collins, Kendall and Michael, 1998. *op.cit.* p. 5.

⁷¹ Rose, 1994 *op.cit.*

Chapter Two *Technology of Health*

The radically new fact about the nineties is the biotechnologies, that is to say the degree of autonomy, mastery, and sophistication reached by technological devices that take 'life' and 'the living organism' as object.⁷²

Of concern to participants of the House of Commons 1999 Study on "The State of Organ and Tissue Donation" was the human body not as a whole but in parts. Reference to "organs and tissues" without mention of persons takes the objectification and use of live parts from dead bodies as nonproblematic. This is based on the argument that replacing body parts "has *become accepted as conventional*, best available therapy for end-stage organ failure, and the transplantation of human tissues has *become common standard of practice* for a wide variety of conditions."⁷³ This position, articulated by the lobby group Organ Sharing Canada, is in keeping with a report by the Law Reform Commission of 1992, general transplantation discourse and is reflected in several documents on transplantation recently produced by the federal government.⁷⁴ Rather than accept that we need to know nothing about transplantation other than its possibility, the question raised by this premise that forms the subject of this chapter is how the replacement of vital parts using the 'living dead' became a therapeutic modality?

The argument made is that it was not the "discovery" of transplantation but the alignment of religion, capitalism and the state to medicine that enabled replacement to become a possible way of seeking to cure. Underlying current "organ donation" debate is the view that the transplant industry proceeds free of vested interests and non-altruistic motives. This "practice of truth" leaves unexamined the reasons indications to transplant widen, why the demand for organs continues to rise, evaluation of transplantation outcomes and the relations between persons and person's bodies re-assembled by this form of treatment. The controversial history and complex networks of prestige and

⁷² Rosi Braidotti *Nomadic Subjects: Embodiment and Sexual Difference in Contemporary Feminist Theory* New York: Columbia University Press, 1994. p. 42.

⁷³ Organ Sharing Canada "Safety of Organ and Tissue Transplantation in Canada." quoted in Therapeutics Products Programme, Health Protection Branch, Health Canada, "Proposed Risk Management Framework to address The Safety of Tissues and Organs for Transplantation in Canada" May 1998 p. 3. (emphasis added) Production of this document was project of the Canadian Association of Transplantation and the Canadian Transplantation Society.

⁷⁴ Law Reform Commission of Canada "Procurement and Transfer of Human Tissues and Organs" Working Paper 66, 1992.

money that hold this *technology of health* in place are contained in the first 'black box' of the transplant episteme.⁷⁵

Two distinct phenomena "opened a clearing" to make vital body parts replaceable: accessing the dead for dissection and making body parts transferable between live persons. This arose through a larger transformation of society in response to the ascendance of medicine. A conflictual transformation of society over 300 years that led to support of medical use of the dead for dissection was followed in this century by unquestioned state endorsement and corporate funding of the medical quest for cure through a technique of hybridization. A critical tool of enrolment emerging from and attendant to these changes that emerged was a distinction between personhood and embodiment. Descarte's conceptual separation of body and soul established a proprietary relationship whereby persons own (and may therefore alienate) their bodies rather than are their bodies. Moving from knowledge to treatment of the body, the uniqueness of persons in their bodies gave way to the identification of sameness, suppression of difference and inducement of sameness to make crossing the boundaries of bioindividuality possible in order to transplant parts. Consequently, use of the dead and the ability to replace blood, tissues and organs with others attributed a value to persons in death and in parts.

As a way of seeking to cure, relationships altered once patients in hospital dying in different orders could be "mixed" to salvage one life. Which direction this could occur in was not always immediately clear. Chimeras was the term adopted to mean mixing two genetic entities. Continuing the life of a human being by making them a chimera thus made someone else a natural resource of raw material to this end. In stark contrast to the way in which transplantation works examined for the chimera here, chapter three and four address two ways in which the other body - the natural resource - has been established to enable saving one life from two through the combination of their bodies.

Encroached upon in the establishment of transplantation is a traditional view of a person as the living body of an individual human being. This implied uniqueness and bodily integrity in life and in death. Use of the dead and use of body parts by others challenged the temporal and spatial boundaries of personhood. How could any one part

⁷⁵ Koenig, B.A. and Hogle, L.F, 1995. *op.cit.*

be an essence of the person if it could be replaced by that of another? In finding other uses, the human body attained value not for the person whose body it is but for others. And not just in life or as a whole, but in death and in parts. This arises from two distinct albeit related turning points in the history of medicine that separated persons from bodies. First was the possibility of treating the dead as a thing rather than the sacred remains of a person. Personhood narrowed to objectify the "deceased" as a "cadaver." Second, transferring the essential fluid of individual life from one person into the body of another subverted the view of embodiment as part of what makes persons unique. 'Self' and 'other' boundaries were further blurred with 'live to live' kidney transfers. Alignment of the state and corporate investment in the effort to hybridize humans entrenched transplantation as a therapeutic modality. Immunological and social tolerance of medical practices that violate the bodily integrity of personhood was achieved by the absence of organized objection. In demonstrating efficacy, a cult of cure gave societal support to medical use of techniques such as transplantation that came to be viewed as "saving" rather than "prolonging" life where all efforts to "fight disease" are justified by the possibility of deterring the failure of death. Examining the choices involved in creating this *technology of health* following a logic of mixing organic 'life' opens up the first 'black box' of the transplant episteme. Power in this process exists in the shaping of what is possible.

2.1 Accessing the Dead: Aligning Christianity, the Law and the State

Breaking the taboo against opening up the corpse over a period of four hundred years legitimized the utilitarian use of the dead. Medical use of the body after life reflects a change in the dominant cosmology bound to the declining power of religion relative to the power of science.⁷⁶ Over this period of medical advancement, the state and

⁷⁶ Reflecting precisely this shift, Pope John Paul decreed in 1999 that hell is not a place after death but state without joy experienced as pain during life on earth. In statements designed to offer more effective religious instruments, hell is no longer to be understood as God's work but a self-imposed state. Noting that today "people speak very little about the next world" some branches of Christianity such as the Jesuits "lament the fact that eternal damnation - once insisted upon - has almost entirely disappeared from the teaching of the church." For them, hell is not on earth, it is the next world that is "absolutely fundamental" to Christianity. Michael Valpy "Throwing cold water on the fires of hell: Pope says hell isn't 'a physical place,' raising some tricky issues" *Globe and Mail* Thursday, July 29, 1999 p. A1.

legal apparatus concomitantly shift from a role of protecting people from medicine to facilitating its advancement. Thus, the shift from public dissection as a punishment for crime to ensure eternal condemnation in 1830 to a symbol of disgrace in 1880 to a not uncommon “gift” a century later offers a case history of social change in the Western world.⁷⁷ Gaining access to dead bodies was accomplished through the gradual accommodation of Christian theology and the state, in law and institutional administration, to the demand of medicine for dead bodies. Responding to a “shortage crisis,” the critical concept altered to allow dissection was the category of persons and meaning of bodily integrity.

Christian belief in the presence of God controlling the universe posited life on earth as only one period of existence. Death was not “the End” but a transition from mortal existence to “the afterlife” of Heaven pending God’s judgement. If positive, the body and soul would be resurrected to rest in peace in the next life.⁷⁸ Proper burial was essential to ensure safe passage of the person to the everlasting happiness that awaited them in Heaven. Within this metaphysical framework of belief in “life after death,” dismemberment was anathema. Monotheistic religions required that the ‘image of the person’ not be altered after death. A Papal Bull published by Benedict VII forbade the practice of altering the body for Catholics. Islam laid down the tenet that “‘You shall present yourself before your God as you were at the time of your death.’”⁷⁹ The offence was to prevent the soul from entering heaven, thereby disrupting nature and God’s will. To deface the remains of the living would bring shame and stigma to all those associated with the person; protecting the honour of one’s kin was a duty in death as much as in life. Thus, the first legal provisions permitting dissection were not designed to advance the

⁷⁷ Ruth Richardson “Fearful Symmetry: Corpses for Anatomy, Organs for Transplantation?” *Organ Transplantation: Meanings and Realities* Younger, Fox and O’Connell (eds.) Madison, Wisconsin: The University of Wisconsin Press, 1996.

⁷⁸ Prior to the possibility of dissection in which DeCartes’ separation of body and soul played a key role, in a world where the Bible was the authority, the body and soul were one. A person (reduced to a soul) could not “own” a body, they were a body. An early “bioethicist” explains: “the Scriptures know no life that is not embodied life; no man whose life is not (in Karl Barth’s terms) the soul (the subject) of his body, and the body of his soul.” Paul Ramsey *The Patient as Person: Explorations in Medical Ethics* New Haven: Yale University Press, 1970. p. 60.

⁷⁹ J.-J. Colpart “Organ Removal and Transplantation: Legislation in France and in Other Countries” *Organ Transplantation and Tissue Grafting* P. Herve, G. Rifle, D. Vuitton, G. Dureau, P. Bechtel & E. Justrabo (eds.) INSERM/John Libbey & Co., 1996. p. 1379.

study of anatomy, "they were in every case a further penalty for crime."⁸⁰ As a way of condemning murderers to eternal damnation, public dissection was a particular infamy that judges could add to the punishment of public execution.

What changed this conceptually was the introduction of the idea of "the body." It was René Descartes' mid-seventeenth century dualistic claim of mind and body as separate entities that is credited for establishing a different understanding of human essence. It aided the practice of dissecting corpses by allowing a metaphysical distinction of the self from the body through a discourse that allowed 'persons,' reduced to the soul, to depart and enter heaven regardless of the fate of their "human remains." In Descartes' schema, advanced two hundred years later, the soul was said to animate the body by means of the pineal body in the brain.⁸¹ In this mechanistic view that critics later implicate as responsible for what they see as the "dehumanization" of the body by modern medicine, "the body dies at the instant its connection to the soul is broken. But the life of the soul remains distinct from and survives after the death of all body parts."⁸² Thus by the twentieth century Christian theologians re-interpreted the "body" half of the idea that the "body and soul" would resurrect after death from literal to figurative.

A second critical alignment facilitating access to the dead was the enrolment of the state. Contestation between the medical profession and citizens opposed to dissection was dealt with by lawmakers through a gradual expansion in the category of persons who could be considered a legitimate object of medical attention upon their death. Anatomical laws of 1831 in England and Massachusetts augmented the legal supply of corpses from prison gallows by granting civil officials permission to surrender for dissection any body that otherwise had to be buried at public expense.⁸³ Such changes responded to two developments. First was public outrage at grave digging exacerbated by news from the British Isles of murders committed for the explicit purpose of selling

⁸⁰ Frederick C. Waite "The Development of Anatomical Laws in the States of New England" *The New England Journal of Medicine* Vol. 233 (24). p. 719.

⁸¹ Martin S. Pernick, "Back from the Grave: Recurring Controversies over Defining and Diagnosing Death In History" *Death: Beyond Whole-Brain Criteria* Richard M. Zaner (ed.) Boston: Kluwer Academic Publishers, 1988. p. 28.

⁸² Gerald P. McKenny *To Relieve the Human Condition: Bioethics, Technology and the Body* New York: State University of New York, 1997. p. 184. Pernick, Martin S., 1988. *op.cit.* p. 28.

⁸³ Frederick C. Waite, 1945 *op.cit.* p. 720.

dead bodies to anatomists.⁸⁴ Second was the effort of the medical profession who lobbied politicians and launched a program of public education informing people of the benefits of medical advancement from the study of anatomy.⁸⁵ Regardless of the successful enrolment this signaled, the law did not reflect a change in attitude - it was only the dead bodies of citizens deemed expendable that were made available. Added to the worst criminals were lesser criminals, then the poor.

Changes in where people died facilitated a greater supply of corpses for dissection. As institutionalization of work and the provision of health care became more common, rules were introduced to allow for the confiscation of any person without relatives to claim them from workhouses or hospitals where they died, or sufficient money to pay for their own funeral. Based on the existing class system in Connecticut, Maine and New Hampshire, soldiers, sailors, members of the Marine Corps and widows of these men were exempted from automatic dissection slated instead for burial at public expense. Tramps, vagabonds and vagrants, by contrast, were excluded from the exemption. Even with stronger laws, medical professionals in New England complained:

This legislation was defective in two major respects, the first being that it was not mandatory, but only granted permission to civil officials to deliver bodies for dissection at their discretion, and the second being that it included several exceptions that tended to nullify its purpose. Officials were not permitted to deliver for dissection the body of any stranger, any town pauper, any person who during life had requested that his body be buried or any person whatsoever if within thirty-six hours a kinsman or friend requested that the body be buried.⁸⁶

In their view, the provision that consent could not be presumed or right to the body exercised where a contrary will was outright stated denied anatomists their material. Similarly, the discretionary power of officials to bury bodies on the basis of personal aversion to dissection or avoidance of making a decision that could bring public criticism from those who had known the dead person in life were seen as weaknesses in the legal support for medicine.⁸⁷ There could be political consequences should a family member

⁸⁴ See the trials of murderers in William Roughead, *Burke and Hare* Toronto: Canada Law Book Company, 1921.

⁸⁵ Frederick C. Waite, 1945 *op.cit.* p. 721.

⁸⁶ *Ibid.* p. 721, 724.

⁸⁷ *Ibid.* p. 722.

discover their relative mutilated by an anatomist. Failure to save a loved one from this fate violated the sacred duty of families to treat the dead respectfully through rituals of proper burial.

The encroachment upon the disenfranchised added further stigma to poverty: "To die without provision for burial became the key indicator of social failure."⁸⁸ While the wealthy remained protected, saving for burial and maintaining family ties became the only way a pauper could secure passage to heaven. Dignity for this segment of society was sacrificed by legislators of the states of New England to accommodate the "desires and advice of the medical profession" by tightening anatomy laws between 1870 to 1898.⁸⁹

Members of a group of named civil officials and employees of political divisions have the duty to notify certain specified legal recipients when a body that must be buried at public expense comes under their control, and when the recipient has made a written request for the body they have the further duty of delivering it to him.⁹⁰

By passing mandatory rules, centralizing control over access to bodies and introducing incentives, dissection was established as the institutional norm. While a board took over the distributive duty required to manage a steady stream of dead bodies, debate turned to who could request burial. The proximity of relations had to be weighed against the request for dissection now that strangers had a sanctioned interest in the dead.⁹¹

With less publicity and the impression that all dead bodies dissected were secured legally due to legislative changes, vocal aversion to dissection abated. While demand remained unquestioned, it did not continue to rise exponentially. Supply of bodies remained contingent, however, on the role of institutions and the rules governing how such places handled dead persons in their care. Only in the twentieth century after institutional change removed virtually all sources of corpses was voluntary bequest of

⁸⁸ Ruth Richardson. 1996. *op.cit.* p. 73.

⁸⁹ Frederick C. Waite, 1945. *op.cit.* p. 723.

⁹⁰ *Ibid.* p. 724.

⁹¹ "The history of the development of laws for the legal acquisition of dead human bodies for dissection in New England covers the more than three hundred years since its first settlement in 1620 and goes back at least another hundred years in English common law. This history in the last one hundred and fifty years has included many endeavors and many disappointments on the part of the medical profession of New England." *Ibid.* p. 723.

dead bodies seriously considered. Three percent of all corpses dissected in England in 1934 came from volunteer donations.⁹² In the space of thirty years, this figure rose to seventy percent such that in the postwar era, a “very significant and remarkable change in public attitude” resulted in more bodies offered than required.⁹³ Ruth Richardson attributes this change to historical developments that promoted trust in medicine. She argues that the success of the medical profession’s appeal for generosity was influenced specifically by the sense of national cohesion garnered during World War II and the implementation of a public health care system.⁹⁴ Others regard the decision by most people not to donate their body to medical science as evidence that aversion to dissection remains widespread.⁹⁵ In the closing decades of this century, the supply shortage has also significantly lessened by a decrease in demand due to changes in medical school curriculum and the invention of mechanical cadavers as an alternative resource.

In sum, dissection of the newly dead contributed to the practice of transplantation in several important ways. Christianity and the state, in law and administration, adjusted to permit and facilitate qualified access to the dead and mutilation of the corpse through changes to ideas of personhood. For the former, adoption of the Cartesian division allowed personhood to be conceptually detached from the body. If the soul, as the essence of the person was located in the mind and left instantly upon death, the body that remained was no more than an object “used” during life on earth. For the latter, gradual liberalization by parliaments of restrictions on whom could be used as a natural resource came at the expense of a particular social group, the value-less, whose ranks were continually expanded through a continual widening of this classification. It was not the state of death but its circumstances and position in life that led some people to become depersonalized “corpses” or “cadavers” upon their death while others retained a relationship to the living world as “deceased” persons. Instead of all persons being qualified to be treated as a full person, the establishment of a category served as the

⁹² Ruth Richardson, 1996. *op.cit.* p. 74.

⁹³ *Ibid.*

⁹⁴ *Ibid.*

⁹⁵ S.J. Youngner “Organ Retrieval: Can We Ignore the Dark Side?” *Transplantation Proceedings*, Vol 22(3): 1014-1015, 1990. p. 1014.

device used to legitimize medical intervention. Within institutional sites, the establishment and enforcement of these distinctions led to the routine use of the dead.

Finally, the impact of dissection on medical knowledge has been hailed as revolutionary. Critical to transplantation was the observation of death as possessing a spatial and temporal pattern as it spread throughout the body. This knowledge contributed to physicians' ability to arrest death and alleviate the suffering of disease through different methods of treatment. As awareness and benefit from increasingly successful medical treatment spread, social attitudes changed to a view of the pursuit of this profession as noble. Seen as doing good, the role of religion and the state came to support dominant practices of medicine rather than protect citizens from surgeons. In facilitating dissection, the domain of medicine moved into previously closed spaces establishing death, the dead and the interior of the body as places where medicine could legitimately intervene. Value to society in using the dead eventually led people to voluntarily choose to be dissected upon their death as a desirable contribution. Setting the Cartesian conceptual separation of mind and body into law, legislation permitting the "giving" of the dead body for dissection established the body as holding a "gift" proprietary status in relation to the person. This set a precedent that would be extended to cover therapeutic use of the body. Unforeseen consequences of legitimate use of the dead to attain knowledge were the attribution of value to death and sanctioning claims on the dead. The objectification of the individual for the sake of others was also established as justifiable, if not ever fully embraced. This meant that death was no longer the end of one's use to society.

2.2 Live to Live Body Part Transfer

2.2.1 *Micro-Parts: Blood*

Building upon the use of the dead for knowledge of life, the second turning point that opened up the possibility of using the 'living dead' for vital organ transplantation was the advent of live to live body part transfers. As the first transplants, blood, bone marrow and corneas taken from one individual were inserted into another as a form of therapeutic treatment. Key resources that came into alignment to aid the accomplishment

of this medical pursuit included state fulfilment of national objectives and private commercial interests.

Part of the invisible that became visible through opening up the cadaver was knowledge of the similarity of the substance of the body. In identifying the characteristics of the interior of the body and understanding the workings of systems and parts people could be distinguished in new ways. At the same time, situating the individual within groupings classified according to cellular type also pointed out degrees of 'sameness'. This occurred through the advent, abandonment and later renewed and explosive pursuit of making parts of the body transferable therapeutic agents. Testing the possibility and limits to transferring body parts, as a process that began over three hundred years ago, has become a widespread medical practice in the twentieth century.

Initiating efforts to replace body parts, a blood transfusion experiment was performed in 1665. The blood of one dog, let out until it died, was poured into the body of another dog while its own blood ran out.⁹⁶ The second dog recovered to live a long life fuelled by another dog's blood. Reaction of the public was characterized by intense speculation, "much of it centering around the commonly held view at that time that blood carried in it the secrets of individuality."⁹⁷ Various witticisms emerged about what would happen if the blood of a Quaker was let into the body of an Archbishop. A transfusion of lamb's blood into a teenage boy in 1667 that ended in disaster led to the end of similar experiments across Europe. After charges of murder were laid and the Pope issued an edict forbidding this practice, work in this area halted for the next one hundred and fifty years.⁹⁸

In 1881 the pursuit to replace blood was resumed. A human-to-human blood transfusion performed in this year by Dr. James Blundell led to his suggestion that only human blood be transferred into other human beings.⁹⁹ Within this restriction on interchangeability, identifying and categorizing types of human blood in 1901 established a further limitation to the transfer of blood based on a principle of sameness. Autonomic

⁹⁶ Dr. T.G. Armstrong "Tissue Transplantation: How Feasible?" *The Ethics of Tissue Transplantation* G.C. Oosthuizen, ed. Cape Town: Howard Timmins. 1972. p. 16.

⁹⁷ Richard M. Titmuss *The Gift Relationship: From Human Blood to Social Policy* London: George Allen & Unwin, 1970.

⁹⁸ *Ibid.* p. 18.

immunological rejection of a foreign substance to protect the individual from the outside world would not be triggered if the blood inserted came from a similar type. Some people were thus considered “compatible.” Organizing individuals into groupings through the classification of tissues refined the rules for transfers: blood had to be replaced by the same kind of blood. Thus, to transfer blood between individuals, biological kinship took precedence.

Although technically feasible, adopting this means of cure entailed crossing a conceptual “barrier” to breaching the boundary between persons. Healthy people had to permit clinicians to take their blood in order for it to be available to treat the ill. But the utilitarian use of the body was sacrilegious within a cosmology in which persons were bodies, their unique essence contained in each part.

For centuries then in all cultures and societies, blood has been regarded as a vital, and often magical, life-sustaining fluid, marking all important events in life, marriage, birth, initiation and death, and its loss has been associated with disgrace, disgust, impotence, sickness and tragedy. Symbolically and functionally, blood is deeply embedded in religious doctrine; in the psychology of human relationships; and in theories and concepts of race, kinship, ancestor worship and the family.¹⁰⁰

The symbolic and sacred meanings of blood restricted its use to social interactions of personal attachment. These now old ideas, reflecting times and places in which the body was strictly one’s own, were discordant to the idea of anonymously pooling and using blood. Those who embraced the “discovery” of the *real* purpose of blood were pleased that,

The growth of scientific knowledge about the circulation of the blood, the composition and preservation of blood, and the distribution of blood group genes throughout the human race has provided us with *a more rational framework*.¹⁰¹

Anyone who asserted that “the blood contained in the body is an inviolable property and to take it away is sacrilege” was dismissed as superstitious.¹⁰² While the attempt to enrol participation on the basis of notions of modernity and scientific progress was successful

⁹⁹ *Ibid.*

¹⁰⁰ *Ibid.* p. 16.

¹⁰¹ *Ibid.* p. 17 (emphasis added)

¹⁰² *Ibid.* p. 16.

for some, accessing blood from citizens on a large scale was not accomplished on this basis. Rather, tapping humans as a natural resource came through a more powerful mode of inscription: world war.

State and commercial interests of the Connaught laboratories coalesced to invest in the widescale use of blood upon seeing the value of medicine to their own objectives. The social and economic imperative to cure W.W.I and W.W.II soldiers who presented a high rate of morbidity and mortality due to injury gave impetus to the pursuit of blood as a therapeutic agent. Research into blood transfusion received funding and a system of collection, purification, storage and distribution was established as part of the nationalist endeavor to fight World War II.¹⁰³ Objections to this practice were overruled by observations of success and the justification that blood transfusions save the lives of precious people.

Connecting scientific rationality to morality, social obligation dictated that citizens donate their "life-restoring fluid" in order to (not prolong the life but) prevent the death of others.¹⁰⁴ As a way to realize the very thought of giving one's blood to another person, campaigns promoted blood as a "gift of life," attaching a familiar concept to explain a novel practice. Soldiers' sacrifice of their life in war to protect the nation could be matched by voluntarily sacrificing a part of oneself for them. Hence, it was not odd but positive that a body part could exist outside the body, live in others and thereby contribute to the public good. Initial debate surrounding the use of blood subsided as the annual rate of donation multiplied over the course of the war.¹⁰⁵ With a "in the flesh" ritual through which civilians could support loved ones at war or fellow citizens in trauma, the practice of giving and receiving blood was normalized.

¹⁰³ Dr. Norma Bethune used blood transfusions to treat the wounded in the Spanish Civil War, 1936-1939. Dr. Charles Best initiated the first blood donor clinics at the University of Toronto in 1939. A private-public financial arrangement supporting Dr. Best's experiments led to the process of fractioning plasma into a concentrate that could be used as a therapeutic agent. After the war, the infrastructure created contributed to the creation of national health insurance. André Picard, *The Gift of Death: Confronting Canada's Tainted-Blood Tragedy* Toronto: Harper-Collins, 1995. p. 17-18.

¹⁰⁴ W.R. Feasby, ed. *An Official History of the Canadian Medical Services, 1939-1945*. Volume 2. Ottawa: Queen's Printer and Controller of Stationary, 1953. p. 378.

¹⁰⁵ Over the entire year of 1941, 36,000 donations of blood were received; by 1942, 11,000 donations were received per month; and by 1943, the monthly rate was over 57,000 donations. In 1944, blood donations topped one million. Influencing the overall volume of national blood was the initial exclusion of women, in addition to men rejected for health reasons. Initially thought to be too fragile, the ban on women was lifted after the raid on Dieppe in 1942. *Ibid.*

With less attention, bone marrow and corneas were also accessed and used for others during this century. Attaining value independent of their owners, these body parts followed a similar course as blood, shaped differently by the property and symbolic meaning attributed to the part.¹⁰⁶ In recent decades an increasing number of body parts including sperm, placenta, foreskin, foetal cells, eggs and umbilical cords have been added to the list of corporeal therapeutic tools (see Appendix A).

Transplantation of micro-parts opened up the real possibility of transplantation from the 'living dead'. Visibility of compatible groupings within which a body part could be transferred indicated that the barrier of individuality in the body could be broken. Transplantation of micro-parts established a distinction between human 'life' and personhood, changing the common conception of the human body. Incremental inclusion of more and more parts in the category 'nonessential to personhood' erodes the view of the body and person as one. While strikingly discordant with "the panhuman assumption that the self and the body are integral to one another," an increasing number of patients benefit from the use of others' body parts as a form of medical treatment.¹⁰⁷ Survival of diseased and dying patients has come to depend upon the donation of blood by the healthy. Commercial interests have also expanded the range of vested interests by using micro-parts in biotechnology products for sale.

Moreover, a discourse was formed to provide a means of gaining access to "spare" blood by establishing taking as an act of generous giving. Sustaining 'live' parts external to the body was moral; giving this kind of 'life' obligation. As treatment appeared successful, use of blood during and following W.W.II expanded and was routinized as standard surgical procedure. Medical professionals adopted a new role of procuring the means of cure by collecting blood and mediating its transfer between bodies. Having another's blood ceased to be seen as a transgression of individuality. Particularly through pooling the resource, "blood" came to be regarded as an abstract object rather than an essential element unique to each person; the minute part reflecting the whole.

¹⁰⁶ Dissemination of new knowledge represented in popular photographs and scientific discourse strongly influence changing public views of parts of the body.

¹⁰⁷ Donald Joralemon, "Organ Wars: The Battle for Body Parts." *Medical Anthropology Quarterly* 9:335-356, 1995. p. 347.

2.2.2 *From Blood to Kidneys: Commercial and State Support*

Continuing the trajectory of using parts of one person to treat another, small teams of doctors sought to make vital organs transferable. Diseases that could be located primarily within one organ might be resolved by replacing the organ, if the immunological rejection of a large part of the body could be overcome. To accomplish this end, surgeons sought linkages with specialists in immunology and physiology in experimental research aimed at making organs transferable.¹⁰⁸ Enabling them to advance this technique for cure was commercial funding of their work. From the perspective of corporations, the potential immune-suppressing drugs and body part products made replacement technology a venture worth pursuing.

Surgical treatment approaches emerge from a long history of removing dead or diseased body parts that cause pain such as teeth, the appendix or stomach. This treatment modality remained limited in its application, however, to less essential parts as death would otherwise result.¹⁰⁹ Of three types of grafts - autologous (self), allogeneic (same species) and xeno (foreign species)—only autologous transfers could be used to treat burn victims by re-distributing skin. The “dream” to be able to replace malfunctioning parts of the body from a synthetic or human source originates in ancient Western history.¹¹⁰ A Greek myth tells of prosthetic parts made from synthetic materials allowing a man with wings to fly.¹¹¹ A fourteenth century legend tells of Christian Saints Cosmas and Damian using a leg from a dead man to heal a patient afflicted with a leg tumour.¹¹² Based on the knowledge of the immune system and success of blood as

¹⁰⁸ Thomas E. Starzl *The Puzzle People: Memoirs of a Transplant Surgeon* Pittsburgh: University of Pittsburgh Press, 1992.

¹⁰⁹ The acceptance of surgery as a legitimate practice is a relevant topic tied to the emergence of anaesthetics that is beyond the scope of this paper.

¹¹⁰ Note that Alonzo L. Plough describes this fantasy more forcefully: The artificial kidney and artificial heart “represent a continuity of a clinical dream, the totally replaceable body.” Alonzo L. Plough *Borrowed Time: Artificial Organs and the Politics of Extending Lives* Philadelphia: Temple University Press, 1986. p. 4.

¹¹¹ Roy Calne *A Gift of Life: Observations on Organ Transplantation* Aylesbury, Bucks, Great Britain: MTP Medical and Technical Publishing, 1970. p. 1.

¹¹² Leonard Barkan, 1996. “Cosmas and Damian: Of Medicine, Miracles and the Economies of the Body.” in Stuart J. Younger, Renée C. Fox and, and Laurence J. O’Connell *op.cit.* It is notable that the man whose healthy leg was removed was not only dead but also an outsider to this community.

transferable, medical scientists began a concerted attempt to make the replacement of malfunctioning organs a reality in the twentieth century.

Soldiers returning to America after W.W.II missing limbs led to the industrial pursuit of prosthetic replacements. The "increased popular interest in 'spare body parts'" was a money making venture justified on the basis of need. Reconstructing the body with implants was advocated on the basis that "modern prosthetic devices can add years to an individual's useful life, improve physical comfort, or in the case of aesthetic implants, improve emotional stability."¹¹³ Synthetic joint replacement with restricted functioning eventually "took" to host bodies leading to the incorporation of artificial parts and their use as replacements in routine treatment decisions. Alongside limbs, synthetic "pacemakers" and heart valves were made to assist organ based bodily functions. Taking these efforts to another scale, a "kidney machine," was designed in 1960 to substitute entirely for the work of the kidneys when both had died, off-setting the spread of death throughout the body. Initiating the incorporation of high technology in standard medical practice, this machine was endorsed in the West as a possible treatment option.

Attempts by the "organ substitution technology" industry to create total or partial cardiac implants to replace the heart remain less successful. The post-world war effort built upon the early development of a whole heart pump in England in 1928 and a whole-body perfusion device in 1935.¹¹⁴ Research on an artificial heart was launched in 1964 by the U.S. National Heart Institute and the National Institutes of Health. Receiving enthusiastic Congressional approval, the hope at the time was that it would be ready to be used as a permanent replacement for a failed human heart by 1970.¹¹⁵ Cardiac replacement devices seemed to offer a "promising line of attack" to reduce high mortality rates due to cardiovascular disease.¹¹⁶ This effort was aborted, however, after repeated

¹¹³ A mechanical heart valve was developed and used in the early 1960s. For a description of "the growing number of artificial organs being manufactured on a production line basis" see Wilfred Lynch *Implants: Reconstructing the Human Body* New York: Van Nostrand Reinhold Company, 1982. p. vii. The only difference with synthetic replacements, at this point, was the overt connection to what became the plastic surgery industry. Aesthetics was a supplementary reason to pursue these creations in addition to cure.

¹¹⁴ Renée C. Fox and Judith P. Swazey, *Spare Parts: Organ Replacement in American Society* New York: Oxford University Press, 1992. p. 101.

¹¹⁵ *Ibid.*; Deborah Mathieu "Decision at the Experimental Stage: The Case of the Artificial Heart. Introduction" Deborah Mathieu ed. *Organ Substitution Technology: Ethical, Legal and Public Policy Issues* London: Westview Press, 1988. p. 237.

¹¹⁶ Fox and Swazey, 1992. *op.cit.* p. 101.

failure of synthetic hearts to function properly. Scientists moved away from the initial project as they realized using nuclear power to fuel the heart was riddled with problems.¹¹⁷ Another research team of Dr. Robert Jarvik and Dr. DeBakey pressed on to develop a different prototype, the Jarvik-7 artificial heart. In 1976 prestigious heart surgeon, Dr. Wilbert Keon was the first Canadian to implant the Jarvik.¹¹⁸ By 1982, after implanting the device in Barney Clarke, who died after several months, the American experiment came to an end. It was found that "for many reasons, confined not only to the morbidity and mortality of the five patients, the permanent artificial heart experiment was a small and short-lived one with several quiet and unofficial endings."¹¹⁹ Since the abandonment of this project in the 1980s, ambitions to make a synthetic heart were lowered to cardiac assistive devices for supportive or temporary usage. By the late 1990s, however, Ottawa's WorldHeart and several U.S.-based companies restarted "the race to market the world's first totally implantable heart."¹²⁰ Approval for human testing of a permanent heart made of titanium and polyurethane is anticipated in Canada for June 2000 with sale of the product targeted for 2001.¹²¹ With an estimated 5,000 Canadian and 425,000 worldwide "potential recipients," WorldHeart is projecting its first profit at \$13 million U.S.¹²²

Efforts to "reconstruct" the human body by machine and synthetic part were matched by greater attempts to make the transfer of live organs from one person to another work. Demonstrating that replacing live organs could become a viable treatment modality, in order to successfully compete for funding and laboratory space, was not easy. Transplant experiments on animals in 1902 and 1905 failed to align foreign parts.¹²³

¹¹⁷ Deborah Mathieu, *op.cit.* p. 237.

¹¹⁸ Pat Bell "Heart Institute beats on its own: 'Financial autonomy' from Civic will make fundraising, finding investors easier, director says" *Ottawa Citizen* October 30, 1998. p. A1.

¹¹⁹ Fox and Swazey, 1992. *op.cit.* p. 100.

¹²⁰ Pat Bell, 1998. *op.cit.*

¹²¹ Bert Hill "WorldHeart readies for business: Executive shuffle precedes human testing of heart device" *Ottawa Citizen* January 6, 2000. p. C3. "WorldHeart hopes to start selling the new device next year in Canadian and European markets if testing is successful."

¹²² Maria Bohuslawsky "Race is on to market HeartSaver: Ottawa's artificial heart project promises to draw much attention -- as long as doctors can keep the technology here." *Ottawa Citizen* January 25, 1999 p. D1. Karyn Standen "Touring Bryden wears World Heart on his sleeve: Once again, he must drum up cash for a long-shot venture." *Ottawa Citizen* August 12, 1998. p. G1.

¹²³ A animal-to-animal kidney transplant operation was attempted in 1902 and a heart transplant performed in a dog in 1905. Dr Gill Langley and Joyce D'Silva "Animal Organs in Humans: Uncalculated Risks and

Surgical techniques could be perfected but overcoming rejection of the foreign organ by the recipient's body following insertion proved a difficult "barrier." Lack of resources to support the concept of live organ replacement caused the abandonment of efforts in the early part of the century until interest renewed in the 1960s. By this time, resources existed for scientists to draw on when seeking financial support to research the idea of transferring an organ from one person to another. In addition to blood transfusion, skin and kidney allograft experiments during World War II demonstrated that a common antigen could "sensitize a recipient to a subsequent allograft of either tissue from the same donor."¹²⁴

Replacement of the kidney forged ahead of efforts to replace other organs, not least because it was a body part that has a pair.¹²⁵ In 1936 the first human to human kidney transplant was surgically performed with the immediate response of rejection by the body.¹²⁶ Knowledge from experiments testing immunological reactions to the transfer of skin between identical twins contributed to a "successful" kidney transplant from a living donor in 1954.¹²⁷ Success was defined at this time by graft function without immediate destruction and rejection by the body of the host.¹²⁸ Reflecting the principle of sameness established through the categorization of persons by blood type, identical twins were found to be the same enough for their kidneys to be interchangeable. By 1955 success among nonidentical subjects were so few that in the United States kidney transplantation was considered "a method of therapy inevitably foredoomed to early failure."¹²⁹ Experiments in France from 1945 to 1951 were also reported to be failures. Patients who received a kidney from a close relative rather than stranger had a better chance but the difference between these bodies led sooner or later to auto-immune rejection. Under

Unanswered Questions" London: British Union for the Abolition of Vivisection and Compassion in World Farming, 1998. p. 33, 45.

¹²⁴ J.E. Murray "Forty Years of Transplantation - Merely A Prologue" *Transplantation Proceedings* 24(5): 1648, 1992.

¹²⁵ "Paired" (kidney) and "non-paired" (i.e. heart, liver) vital organs is a medical distinction used henceforth in this thesis.

¹²⁶ Dr Gill Langley and Joyce D'Silva, 1998. *op.cit.* p. 33.

¹²⁷ J.E. Murray, 1992. *op.cit.*

¹²⁸ Lesley A. Sharp "Organ Transplantation as a Transformative Experience: Anthropological Insights into the Restructuring of the Self" *Medical Anthropology Quarterly* 9(3), 1995. p. 358 (357-389)

¹²⁹ Gordon Wolstenholme and Maeve O'Connor eds. *Law and Ethics of Transplantation Ethics in Medical Progress*, The Ciba Foundation London: J & A Churchill Ltd. (Conference proceedings first published in 1966 as *Ethics in Medical Progress: with Special Reference to Transplantation*) p. 66.

these conditions, replacement was a way of treating illness limited to identical twins. Breaching the uniqueness of bioindividuality for an entire organ required a step beyond compatibility: suppression of bodily resistance to foreign parts.

A chemical compound created in 1961 called azathioprine prevented the abandonment of efforts to replace organs by providing the mechanism to mix self and other. It appeared to overcome the sameness limitation by inhibiting the immune system enough to prevent immediate rejection. Use of this innovation to force the crossing "made it feasible to reexamine the possibility of performing transplants between non-related individuals."¹³⁰ Through the suppression of difference by azathioprine based drug cocktails, survival rates climbed from 10 percent to 50 percent.¹³¹ Transferring organs between different bodies thus found a pharmaceutical ally that allowed the pursuit of transplantation to proceed.

2.2.3 *Alignment of the State*

With signs of success from the use of kidney machines and, to a lesser degree, kidney transplants, organ transfers received government endorsement. In 1972, a United States congressional decision endorsed dialysis and kidney replacement as legitimate forms of medical therapy. In a highly politicized debate, these two treatment modalities were elevated from the status of experimental to therapeutic procedures.¹³² While pleased, even transplant surgeons found this outcome amazing: "not only were organ-recovery systems primitive, but the one-year success rates of transplantation were 60 percent at best, unless one administered intensive, frequently fatal, levels of immunosuppression."¹³³ The standard of evidence required to demonstrate treatment efficacy when applying for Medicaid was usually much higher. Studying the details of the decision to fund End Stage Renal Disease (ESRD) treatment, anthropologist Alonzo Plough found the

¹³⁰ Alfred M. Sadler and Blair L. Sadler, (eds.) *Organ Transplantation -- Current Medical and Medical-Legal Status: The Problems of an Opportunity* Maryland Academy of Sciences Symposium, National Institutes of Health, 1969. p. 6.

¹³¹ *Ibid.* p. 17.

¹³² U.S. *End Stage Renal Disease Act*, Sec. 2991 of the Social Security Amendments of 1972. *Public Law* 92-603. Barry D. Kahan "Organ Donation and Transplantation - A Surgeon's View." *Organ Transplantation: Meanings and Reality*, Younger, Fox and O'Connell, 1996. *op.cit.* p. 132.

¹³³ Barry D. Kahan, 1996. *op.cit.* p. 132.

evidence irrelevant.¹³⁴ In the absence of any explicit assessment such as randomized clinical trials, Congress members based their decision on two reports. The *Kidney Disease Program Analysis* report emphasized the economic cost of renal morbidity and mortality and The Gottschalk Report described policy problems posed by treatment choices and declared the two main treatment modalities sufficiently well advanced.¹³⁵ The dominant theme at the hearings was the devastating personal and social costs of kidney disease punctuated by stories of personal encounters with such patients.

The simple dichotomy of life versus death presented a strong rhetorical framework that gave momentum to a moral definition of the problem -- the absence of treatment for any ESRD patient could not be considered ethical. Public opinion demanded federal intervention to ensure that access to treatment would be independent of the ability to pay for these expensive therapies. Federal policy regarding ESRD developed within a highly charged environment where a policy to deliver services preceded an assessment of the appropriate use of ESRD technology.¹³⁶

It was on this basis that state and federal levels of government extended medical insurance to cover dialysis and renal transplantation treatment, regardless of the recipient's age or diagnosis.¹³⁷ Providing a national treatment program for all citizens in need echoed the Canadian endorsement of national universal medical coverage only five years earlier. However, by 1986 renal disease was still the only illness that qualified for full treatment cost coverage for almost all patients under Medicaid.¹³⁸

Public funding for dialysis and kidney transplantation thrust these treatment options into the mainstream. Part of what propelled the scale of investment in this *technology of health* in the United States was the structure of the health care system whereby new disease centres opened up across the country in private hospitals and clinics in response to the availability of public funding for kidney services.¹³⁹ Access to dialysis

¹³⁴ Alonzo L. Plough, 1986. *op.cit.*

¹³⁵ *Ibid.* p. 117

¹³⁶ *Ibid.*

¹³⁷ Transplant surgeon Barry D. Kahan argues to the contrary that the transplant enterprise has undergone unprecedented public scrutiny in the United States compared to other high technology medical procedures. 1996. *op.cit.*

¹³⁸ Alonzo L. Plough *op.cit.* p. 119.

¹³⁹ *Ibid.* and Fox and Swazey 1992. *op.cit.*

and transplantation effected demand and, in Alonzo Plough's findings, impinged on "central elements of physician decision making such as choice of therapy."¹⁴⁰

2.2.4 *Medical Adjustment*

Use of parts of the human body as therapeutic devices constructed what could be considered a 'double medical gaze'. Extending the value found in using the dead for dissection into life, patients were no longer subjects in relation to physicians, they were also objects. As a consequence a "pragmatic principlism" was introduced into medical decision-making based on the truth that "human bodies have value, and not just to the persons whose bodies they are."¹⁴¹ Objectification did not present itself as a problem, however, until the advent of attempts to transfer kidneys. Taking the blood of a patient for another was acceptable on the basis that blood was regenerative.¹⁴² Following experimentation, it was determined that removing a limited quantity did not cause harm to the person. Although this pattern was repeated for the kidney demonstrating that a person could live without two, and one could therefore be considered "spare," the objectification and possible harm inflicted on the live "source" troubled physicians.

In using this *technology of health*, the obligation to follow the professional commitment to do everything possible to prolong the lives of ill patients conflicted with the constraint not to violate the most basic moral tenet of their profession to do no harm.¹⁴³ Patients could be maimed in surgery only on the basis that it would improve their health. Maiming a "live donor" patient for the sake of another thus presented a problem. It was argued at a 1966 conference in London held by the CIBA Foundation that "the operation on the donor is not a medical procedure at all; it is not making a sick person well but a well person sick."¹⁴⁴ Using live patients as "the direct means to an end desired," was morally untenable.¹⁴⁵

¹⁴⁰ *Ibid.* (Plough) p. 120.

¹⁴¹ Thomas H. Murray "Gifts of the Body and the Needs of Strangers" *Hastings Centre Report*, p. 30-38. April, 1987. p. 30.

¹⁴² Replenishable, and ease of exit from the body. became two criteria that serve in "Gift Acts" as the basis for marking a distinction between body parts a person can commodify versus give away as a gift. On this basis blood and sperm were given a different status than all other body parts.

¹⁴³ Fox and Swazey, 1992. *op.cit.* p. 39.

¹⁴⁴ Gordon Wolstenholme and Maeve O'Connor, 1986. *op.cit.* p. 132.

¹⁴⁵ *Ibid.*

For this reason, ethnographic studies found medical teams holding deep-seated misgivings about “inflicting irreversible damage on a healthy person.”¹⁴⁶ As one of the early dilemmas that gave rise to the profession of bioethics, this situation was first overcome by the assumption that love and selfless generosity served as an adequate justification to remove a body part from a person for someone else. Physicians were nonetheless uncomfortable with fostering a community attitude that would pressure a relative to serve as a donor. Relationships between donors and recipients were also found to be complex as the kidney, holding the status of “gift,” was never viewed as a fully alienable object giving without attachment.¹⁴⁷ Consequently, transplant surgeons turned to the “dead” as a source of organs, rather than the living, as standard practice. This unofficial norm was adhered to by most in the field until re-consideration in the 1990s due to a declared “shortage crisis” in the supply of organs.

2.3 Access and Use of the ‘Living Dead’

The fact of death prior to 1968 was signalled by cessation of the heart. To meet this standard for legal reasons, physician-researchers conducting kidney or liver transplant experiments on humans took organs from patients with destruction of the brain only after disconnecting the ventilator (“pulling the plug”) and waiting five to thirty minutes for the heart to stop.¹⁴⁸ At this point death was pronounced and artificial circulation restored using a heart-lung machine. This legal requirement of waiting for the heart to stop was not looked upon favorably, however, since the wait for “death” was a period in which surgeons stood watching the cessation of their precious material. The organs to be transplanted “were variably damaged by oxygen starvation and the gradually failing and ultimately absent circulation.”¹⁴⁹ Maintaining a strong heartbeat and good circulation in a “cadaver donor” was preferable from their perspective to improve the

¹⁴⁶ Fox and Swazey, 1992. *op.cit.* p. 39.

¹⁴⁷ *Ibid.*

¹⁴⁸ Thomas Starlz, 1992. *op.cit.* p. 148 (Five to ten minutes is the time lapse stated here, at page 104 it is five to thirty).

¹⁴⁹ *Ibid.* p. 148.

quality of the organs for their patients. How death occurred in relation to organ procurement did not cause a stir until the organ removed was the heart.

When Dr. Christiaan Barnard of South Africa performed the world's first heart transplant in 1967, a media event was created that woke the world to what was happening in the field of experimental transplant research. Prior to overcoming problems of organ rejection from non-related donors, surgeons eager to advance the possibility of curing heart disease had started experimenting with the viability of replacing other vital organs. Seen as the seat of the soul, the heart transplant violated the standard conception of death. Two reactions emerged in the Western world. First was praise for a "medical miracle" for the life of Louis Washansky that promised to deliver people from death. Second was offence since Denise Ann Darval could not have been dead if her heart was still beating. Chapters three and four address each of these responses to demonstrate how, in the West, the first voice prevailed through adjustments made to accommodate this therapeutic modality. To legitimate medical intervention on the dying not to save their life but that of another, chapter three shows how disagreement over when organs could be procured was 'black boxed' by the *dividing practice* of re-defining death to 'make visible' a live/dead patient as a legitimate object. Institutional acceptance of Harvard Medical School's 1968 declaration that 'irreversible coma' could be considered death was one way experiments removing parts of people was able to proceed in the West.

Equally important was the meaning attributed to this *technology of health*, subject of chapter four, through a discourse of donation that granted "the body" the status of "gift" and defined the taking of organs as a noble act of giving. The positive knowledge that would form public debate over the next thirty years built upon ideas already encoded into law. Anatomy acts to allow access to bodies for "anatomical examination" were added to in the 1950s to permit the removal of corneas from the dead for therapeutic purposes. To *Uniform Cornea Transplant Acts*, *Uniform Anatomical Gift Acts* were added in 1968 to enable removal of all tissues for use by other patients as therapeutic agents "after death." Following proclaiming the latter law in Maryland in 1968, the American Bar Association and numerous medical groups approved and adopted it immediately. One year later, 25 states had passed the legislation. In Canada, a Uniform

Law Conference held in 1971 recommended the same type of *Uniform Human Tissue Gift Act* which passed as legislation in all provinces between 1971 and 1989.

In spite of the fact that it was only while 'alive' that organs possessed value, "gift" legislation treated intervention on the live/dead patient as merely an extension of intervention into the dead for knowledge. The language used to account for transplantation framed the use of the body in parts as a desire, opportunity and right to facilitate "the new opportunity to save human life."¹⁵⁰ The alive/dead status of the giver was treated as nonproblematic, with reference to 'imminently dying', 'after death' and 'at death' used as synonyms. This confirms the profound change in attitude Ruth Richardson observed in willingness to be dissected after death based on the rise in volunteer donations from three percent to seventy percent from the 1930s to the 1960s.¹⁵¹ By establishing the body as holding a quasi-alienable proprietary status of "gift" in relation to the person, the passage of such acts embedded the Cartesian view into law. As I later show, legitimating and justificatory mechanisms were mobilized with the effect that objection to using a particular category of the dying as a source of organs did not disappear but faded out or were silenced.

2.3.1 *Securing Hybridization: Corporate and State Support*

Thus, as forms of power aligned to make the natural resource body by enabling the removal of organs from the 'brain dead', medical scientists pursuing transplant research continued to focus their research on strategies to overcome rejection. An explosion of heart transplant experiments followed Barnard's first in medical centres around the world. Initial enthusiasm gave way to disfavour as results failed to support the promises and hopes of medical professionals. Consistent failures led the Montreal Heart Institute to place a moratorium on heart transplants in 1970.¹⁵² Media attention could be hopeful or critical, occasionally presenting "the 'transplanter'" as "a taker of organs rather than as a healer and the patient's guardian."¹⁵³ Some members of the

¹⁵⁰ Sadler and Sadler, 1969. *op.cit.* p. 36.

¹⁵¹ Ruth Richardson, 1996. *op.cit.* p. 74. (As described earlier in this chapter, see page 7)

¹⁵² Renée C. Fox and Judith P. Swazey *The Courage to Fail: A Social View of Organ Transplants and Dialysis* Chicago: The University of Chicago Press, 1978 (2nd ed., revised) p. 109.

¹⁵³ *Ibid.* p. 132

medical profession found the politicization of therapeutic innovation and researchers attitudes disturbing for violating "the professional norms of privacy, modesty and disinterestedness."¹⁵⁴ Criticism slowed down over the course of the 1970s turning after 1973 when fascination turned to patients who had survived as long as two years.

Sudden attention towards transplantation as the new hope for curing fatal disease led American transplant surgeon Thomas Starzl to ask in a 1978 speech whether "the integrity of the field had been undermined by persistently optimistic claims in kidney transplantation that were deceptive at best and potentially fraudulent at worst."¹⁵⁵ He noted that very few transplant centres published their results and those that did reported unsatisfactory graft survival and high patient mortality. "The public received a far more optimistic message."¹⁵⁶ In reality, the vast majority of experiments in replacing organs continued to be unsuccessful. Experimental transplant research programs for other organs fought for survival. Within the profession, doctors at the Pittsburgh medical centre denounced liver transplants as unrealistic and unethical. Public response to the death of research participants provoked radio talk shows to conduct surveys on whether liver transplant trials should be shut down.¹⁵⁷

Without the support of their colleagues, a small group of surgeon/researchers connected by institutional links and a shared professional circle forged ahead through the 1970s in pursuit of replacement as a way to alleviate the suffering inflicted by chronic disease. Within a medical sub-culture of camaraderie and competition, transplant surgeon J.E. Murray describes their "lone quest" as driven by a moral commitment to find a cure for their patients.¹⁵⁸ Communication was facilitated by a pharmaceutical company sponsorship of the journal *Transplantation Proceedings* and annual international conferences hosted by the Transplantation Society. Coalitions between surgeons and physicians whose specialities are defined by organs (nephrology, hepatology and cardiology) was described by Dr. Starzl as a key to success.¹⁵⁹

¹⁵⁴ *Ibid.*

¹⁵⁵ Thomas E. Starzl, 1992. *op.cit.*, p. 208.

¹⁵⁶ *Ibid.*

¹⁵⁷ *Ibid.* p. 247 and 244.

¹⁵⁸ J.E. Murray, 1992. *op.cit.*

¹⁵⁹ Thomas E. Starzl, 1992. *op.cit.* p. 246.

Under pressure to make replacing body parts work, different approaches were taken to weaken the immune system. "Every new lead worldwide for a dozen years had fanned enthusiasm at first, followed by disappointment."¹⁶⁰ Modifying x-ray treatment and removing lymphocyte cells responsible for rejection only minimally improved the survival rate of kidney transplants. Pharmaceutical companies funded transplant teams in "the race" to be the first to make the replacement of various organs viable.

In the late 1970s Jean Borel of Sandoz Corporation, a Swiss pharmaceutical company, developed cyclosporin. Basic immunology had "undergone a revolution" from the early 1960s to late 1970s independent of transplantation.¹⁶¹ Borel's research in rats demonstrated that this drug inhibited only part of the immune system, avoiding the problem of overall immune function suppression. However, in 1977 Sandoz executives decided to discontinue this research due to cost and a judgement that the limited market would never allow them to recover a return on their investment.¹⁶² Borel's "one-man crusade within his company to save his precious drug from abandonment" and the appeals of David White and Roy Calne, two transplant surgeons from Cambridge, who had conducted successful experiments with the drug, convinced Sandoz's executives to reverse their decision.¹⁶³ Contributing to this was London Ontario's Transplant Centre, chosen "as one of the first centres worldwide" in 1979 by Sandoz and supported by the Richard and Jean Ivy Fund and government funds, to conduct clinical trials on transplant patients.¹⁶⁴ Results from trials in Canada, England and the United States over several years demonstrated an increase in the survival rate of kidney transplant recipients from fifty-five percent to eighty percent after one year.¹⁶⁵ This led to the release of cyclosporin by the United State's Federal Drug Administration in 1983. Cyclosporin's specificity to target a relatively narrow range of immunosuppression overcame the fifteen year effort that had created an impasse in transplantation. It came with negative side effects but

¹⁶⁰ *Ibid.* p. 210.

¹⁶¹ *Ibid.* p. 209.

¹⁶² *Ibid.*

¹⁶³ *Ibid.* p. 210.

¹⁶⁴ London Health Sciences Centre, Multi-organ Transplant Service.
<http://www.lhsc.on.ca/transplant/hxtx1hsc.htm>

¹⁶⁵ *Ibid.*

“cocktails” of counter-acting drugs were designed to mitigate these damages enough to claim this drug “successful.”

Cyclosporin was the “conceptual leap” in therapy that together with the assistance of the public, the media and the federal government, “markedly accelerated transplant technology transfer from the experimental arena to clinical practice.”¹⁶⁶

The improved (albeit imperfect) results of regimens containing cyclosporine were evident in a variety of treatment settings. Its superior, reasonably reliable effects led to a precipitous knighting of CsA, in the belief that its vasculopathic side effects were intrinsically susceptible to solution - in due time. In short, the introduction of CsA brought transplant surgeons out of the cave and into the daylight. Unfortunately, it took a few years for our eyes to adjust and see the long-term limitations intrinsic to the therapy.¹⁶⁷

Survival statistics jumped after recipients began taking daily dosages of cyclosporin. Although the seriousness of side effects gave medical staff different opinions of “success,” the trend towards longer post-surgery life changed transplantation from an extremely risky to a last-resort consideration.¹⁶⁸ With sufficient evidence to justify further endorsement, transplantation experienced a “boom.” In 1982, 103 transplants were attempted in the United States. One year after cyclosporine received approval in 1983, 346 surgeries were performed. By 1988, only five years later, the number was 1,647 per year.¹⁶⁹ With daily regimes of immunosuppressant drugs necessary to inhibit rejection Sandoz corporation realized reneging on their plan to abandon transplantation research was their best decision ever.

¹⁶⁶ Barry D. Kahan, 1996. *op.cit.* p. 127.

¹⁶⁷ *Ibid.* p. 130. Not until the recent transplant of a non-essential organ has the public been made aware that recipients actually have an “increased risk of infection, an increased risk of some cancers and an increased risk of some metabolic diseases.” Dr. Barker quoted in Ian Phillips, Associated Press “Recipient of new hand can wiggle his fingers” *Globe and Mail*, Friday, October 16, 1998. p. A9.

¹⁶⁸ A study of the problems of measurement found this result: “A surgeon in a London hospital transplanted the livers of ten patients. Two died, and eight survived. Of the latter, one was a young woman, whose cancer of five years earlier had returned, while the liver of another was slowly being rejected, necessitating a second transplant. Of the remaining six, only three were able to resume normal working lives. Asked about his success rate, the surgeon claimed eight out of ten. Indeed, he was prepared to claim nine out of eleven after the retransplant (since he counts livers, not people!). An immunologist, who felt the surgeon should not have operated on the young woman, put the rate at seven out of ten, while an administrator put it at six out of ten. The nurses, most aware of the quality of the lives of those who could not return to work, put it at three out of ten.” From “Managing the Care of Health and the Cure of Disease, Part I: Differentiation” Sholom Glouberman and Henry Mintzberg unpublished paper, February 1998.

Evidence that transplantation was an effective form of treatment contributed to a surge in demand. Addressed in chapter four, public appeals for organs and money needed for transplant surgery contributed to a shift in understanding this *therapeutic modality* as “saving” rather than “prolonging” life. Media attention to transplantation in the United States led to federal legislation that granted public funding of expensive drugs such as cyclosporin and private-sector administrative units called organ procurement agencies. At the same time, the prohibitive cost of transplant surgery ceased to be a barrier to access this service.¹⁷⁰ Private insurers would only fund treatment modalities considered therapeutic, basing their judgement on Medicaid’s classification scheme which listed all transplants except for the kidney as experimental. A three day trial held by the special Consensus Development Review, organized through medical-political connections, changed this by declaring liver transplantation therapeutic.¹⁷¹ Following the pattern of the kidney decision, the outcome of the Review board hearing was influenced by a “mute but eloquent” group of eight children who had survived for more than ten years.¹⁷² Interpreting the ruling as giving “a sweeping mandate to go forward with development of this field,” liver transplantation experienced a “gold rush” after the decision.¹⁷³ Surgeons flocked to the liver transplant centres in Colorado, Minneapolis and Pittsburgh to be trained to set up their own transplant centres.¹⁷⁴

In Canada, government endorsement of transplantation was equally strong but without public consultation. With a national, universal health care system, decisions on which treatments are considered experimental or therapeutic are made within health

¹⁶⁹ Donald Joralemon, 1995. *op.cit.* p. 335.

¹⁷⁰ Notably, patients susceptible to infection due to poor living conditions remain ineligible for a transplant unless their post-surgery home environment can be changed. This was a point not raised until recently in South Africa with respect to Dr. Barnard’s tertiary care medical facility given priority for years instead of primary care for the squatter settlement twenty miles away where nearly 500,000 live in abject poverty. Seen as part of the legacy of apartheid, heart transplantation has now “become a metaphor for the misallocation of resources.” Alexandria Niewijk “Tough Priorities: Organ Triage and the Legacy of Apartheid” *Hasting Centre Report* 29(6): 42-51, 1999. p. 42.

¹⁷¹ Thomas E. Starzl, 1992. *op.cit.* p. 256. As mentioned in chapter four, Starzl attributes his meeting with the U.S. Surgeon General as the reason this review occurred in 1983, albeit not the reason for the outcome.

¹⁷² *Ibid.* p. 256.

¹⁷³ *Ibid.* p. 257.

¹⁷⁴ *Ibid.* p. 258. “What good was it to develop a procedure if less than five or six people in the world were capable of performing it?” This operation required a “virtuoso performance and even then resulted in the death of 5 to 10 percent of patients in the operating room or shortly afterward.”

ministries. By the mid-1980s if not sooner, heart, liver, kidney and bone marrow were considered therapeutic, pancreas, lung and heart/lung experimental.¹⁷⁵ As Plough found for kidney transplants, government policy “to deliver services preceeded an assessment of the appropriate use of End Stage Renal Disease technology.”¹⁷⁶ Provinces, responsible for the administration of health care services, thus moved separately to fund urban-based experimental research units as they grew into transplant centres. This would by the late 1990s be critized as developing in a “patchwork” fashion, lacking national co-ordination.¹⁷⁷ Driving the expansion of services was the quandry of a publicly funded health care system that a lack of service availability in Canada results in referral to foreign clinics at greater expense. Federal government guidelines for *Vital Organ Transplant Centres* released in 1986 supported expanding transplant services in Canada on this basis.¹⁷⁸ To stay ahead of a projected leap from 972 renal, heart and heart/lung, bone marrow and liver transplants in 1985 to 91 per million in 1990, kidney transplant centres had to start offering other transplants. With no evaluation of quality of life, survival rates for liver, kidney and heart transplant patients were described at this time as “better than 50 percent.”¹⁷⁹ Although anticipation of improvement in survival rates was offered as the rationale for investment this document suggests that demand was the real driving force.

Funding allowed transplant centres to expand along lines similar to London Ontario’s University Hospital which “established itself internationally as a centre for multi-organ transplantation” and received funding from the provincial Ministry of Health in 1987 to build the 12-bed Multi-Organ Transplant Unit.¹⁸⁰ Specialized teams of transplant experts developed from then on, adding physicians, nurses, technologists,

¹⁷⁵ Canada, 1986. “Vital Organ Transplant Centres.” Ottawa: Department of Health and Welfare. Health Services Directorate, Health Services and Promotion Branch, Report of the Sub-Committee on Institutional Programs, Guidelines for Establishing Standards for Special Services in Hospitals p. 3.

¹⁷⁶ Alonzo L. Plough, *op.cit.* p. 117

¹⁷⁷ The criticism was made in 1994 document by Organ Sharing Canada and accepted by Health Canada. This is evident in the reproduction of part of the Organ Sharing Canada document in “Proposed Risk Management Framework to address the Safety of Tissues and Organs for Transplantation in Canada” Health Canada, May 1998. *op.cit.* See footnote 73, page 26.

¹⁷⁸ Canada, 1986. “Vital Organ Transplant Centres” *op.cit.*

¹⁷⁹ *Ibid.* p. 1.

¹⁸⁰ London Health Sciences Centre, Multi-organ Transplant Service, <http://www.lhsc.on.ca/transplant/hxtxlhsc.htm>

therapists, social workers, and recipient coordinators to the original collection of surgeons servicing the organ-dying. Driven by prestige and status, the specialization and competition of transplant centres to expand the “success” of this *technology of health* has led to the improvement in survival rates and organ rejection rates from 1984 onwards. Potential recipient selection criteria have also loosened as research, including that done in transplant patients, widened indications to transplant from 1984 onward to include a broader range of diseases now known to be associated with and treatable by the replacement of a particular organ. Another consequence, however, that has resulted from a level of competition between transplant centres described as a “battle for supremacy” is a fight over access to organs to enable their work. Geographic boundary disputes over the jurisdictions of “fiefdom” transplant centres came to the fore towards the end of the 1990s raising questions of the scale of equal access to organs relative to the cost and time limitations of transporting organs.¹⁸¹ The unmentioned subtext to this debate within the transplant community is the higher incidence of brain-first as a death order in larger centres where violence and automobile crashes are more prevalent. Trouble sharing organs among centres underlay the politics of the House of Commons Event in 1999.

2.3.2 *Chimerism for Everyone: Investment in Research*

From the mid-1980s to 1999, the transplant industry expanded to large-scale, international proportions with research in three areas: feasibility, expansion and new ‘donor’ sources. In the absence of technology assessment and quality of life studies, an extensive entrenchment of interest in this *technology of health* has proceeded, making transplantation appear unstoppable. Academic and clinical research units in transplantation have multiplied, journals specific to transplantation began in the late 1960s gained at least five others with regular articles on transplantation spanning into at least thirty other medical journals. An American and Canadian Transplant Society of surgeons developed alongside national branches of the Association of Transplantation counterpart organization for allied professionals, both of whom meet at annual conferences. Since the cyclosporin “break through,” the pharmaceutical industry has

¹⁸¹ Peter A. Ubel and Arthur L. Caplan “Geographic Favoritism in Liver Transplantation -- Unfortunate or Unfair?” *The New England Journal of Medicine* 339(18): 1322-1325, 1998 p. 1322.

acted as the primary funder of the research and information sharing of the “transplant community.” From a corporate perspective each surviving recipient’s dependency on a daily regime of immunosuppressant drugs represents profit. In producing drugs or body parts, this *technology of health* fits a capitalist economic system dominated by large pharmaceutical companies investing in the new industry of biotechnology.

Although “accepted as conventional” and used as a “common standard of practice,” long-term, permanent replacement of organs has remained elusive. This is in spite of the widening range of efforts and investment in transplantation over the last thirty years. While survival rates show improvement and add years to lives, this means of treating organ-ill patients remains a form of therapy - not a cure. In 1998 survival rates, not measuring quality of life, ranged from 50 per cent at five years for liver; 78 and 91 per cent over 3 years for kidney, 50 per cent at 5 years for lungs and 70 per cent at four years for the heart.¹⁸² Life-long immunosuppression was not the panacea originally thought. In spite of clinical routinization of transplantation, infections, malignancies and end-organ toxicity side effects remained problems.¹⁸³ Numerous approaches continue to be researched as means to increase survival rates by preventing organ rejection. In the meantime, “retransplants” have become relatively common as a means of supporting recipients when the organ ‘dies’ first.¹⁸⁴ But, this increases pressure on and is limited by the supply of organs, in addition to raising questions about appropriate allocation rules.

By 1989, the “unqualified enthusiasm” for cyclosporin as transplantation’s “miracle drug” gave way to more balanced recognition of its strengths and weaknesses.¹⁸⁵ FK 506 was the new drug in a series of new immunosuppressive agents hailed as the next answer. After a decade of research pursuing immune system suppression through pharmaceutical post-transplant therapy, a new approach evolved. Building on the

¹⁸² Alonzo L. Plough *op.cit.* p. 43; Dr. Gill Langley and Joyce D'Silva *op.cit.* p. 24, 39, 45.

¹⁸³ Exner BG, Acholonu IN, Bergheim M, Mueller YM, Ildstad ST “Mixed allogenic chimerism to induce tolerance to solid organ and cellular grafts.” *Acta Haematol* 1999; 101(2):78-81.

¹⁸⁴ Alternatively, if the ‘body’ died first, organs could be removed and transplanted into another body. With this change, persons, bodies and body parts form independent biographies, with the record at an organ having “lived” in (or supporting the life of) three bodies. This is described on a transplant centre’s webpage, in 1993, “a heart transplant patient died suddenly, and this heart was then transplanted into another patient (one heart has supported three lives).” This occurred at a hospital in Switzerland. London Health Sciences Centre London’s Multi-organ Transplant Service “Important Dates in Transplantation” <http://www.lhsc.on.cs/transplant>

¹⁸⁵ Fox and Swazey, 1992. *op.cit.* p. 4.

automatic migration of organ and host cells into one another as the foreign part functions within the systems of the body, scientists began investigating the possibility of inducing “states of antigen-specific unresponsiveness” for “true tolerance” without the need for immunosuppression.¹⁸⁶ By increasing the mixing of the two bodies at the cellular level through a bone marrow transplant, this route to prevent rejection came to use the term chimerism. Originally used in ancient Greek mythology to describe half human-half animal beings, the medical use of this term is defined as the coexistence of two genetically different cells in an individual. Experiments on animals demonstrated that “the chimeric immune system” recognizes donor antigen as self, yet is capable of mounting attacks on third party antigens.¹⁸⁷ A chimerical state gained credence towards the end of the 1990s as the biologic explanation for successful organ as well as bone marrow transplantation.¹⁸⁸ Removing the difference of uniqueness to fool the body into treating ‘other’ as ‘self’ creates the ‘sameness’ necessary for re-building people as a composite of replaceable parts.

Regardless of limited success, other physician-researchers devote their effort to expanding the application of this therapeutic modality. From the mid-1980s onward, the application of transplantation has expanded by range, number and combination of body parts. By 1988 liver transplants were performed for more than 60 distinct diseases and limitations of age were lifted.¹⁸⁹ Similarly, the advent of “multiple-organ” abdominal transplants removed the limiting factor that illness must affect only one organ of the body. In the late 1980s, pancreas, bowel, lung and liver were added to the list of replaceable parts. By 1999, one brain dead body could “yield” thirty-nine parts to as many as twenty-six different people (see Appendix A). In 1998, transplantation began to expand to non-vital organs to replace parts lost due to injury or disease. A forearm and hand transplant for a dismembered person raised controversy over the ethics of fatal

¹⁸⁶ *Ibid.* p. 7.

¹⁸⁷ Gammie JS, Pham SM “Simultaneous donor bone marrow and cardiac transplantation: can tolerance be induced with the development of chimerism?” *Curr Opin Cardiol* 1999 Mar, 14(2): 126-32.

¹⁸⁸ Starzl TE, Demetris AJ, Murase N, Valdivia L, Thomson AW, Fung J, Rao AS “The future of transplantation: with particular reference to chimerism and xenotransplantation” *Transplant Proc* 1997 Feb-Mar;29(1-2):19-27

¹⁸⁹ Fox and Swazey, 1992 *op.cit.* p. 8.

immunosuppressant side effects versus arm replacement.¹⁹⁰ Nonetheless, five months after the first surgery in 1998, five more disabled people were returned to "normal" with the forearm and hand of another. To restore cancer victims' speaking and eating ability, a world first tongue transplant was being planned in January of 1999 and full face transplants were being researched to treat burn victims.¹⁹¹ Continuing the race of transplant centre competition, that led to the world's first heart transplant, only months later American transplant surgeon Robert White announced that he is ready to harvest an entire body onto the head of a quadriplegic recipient.¹⁹²

Media coverage of the quest to make more and more body parts interchangeable as a form of treatment pursued in the late 1990s, extends the first Western response to transplantation of portraying these efforts as fascinating "medical miracles." Without any mention of the source of "spare" arms, tongues, faces and entire bodies, the second response, concerned with the donor, is absent. Only in articles covering the shortage of organs or the third area of profit-driven research to create new sources of organs are "donors" mentioned. Rather than questioning demand, the shortage of organs is claimed to be necessary. The imperative to create chimeras results in the imperative to create natural resources either by increasing the number of human donors, 'growing' organs from human "stem cells" or genetically engineering pigs to be human enough to use but animal enough to kill.¹⁹³ Making xenotransplants work is also intended to expand the treatment regimen of replacement from terminal patients to those with less threatening stages of organ disease.¹⁹⁴ Corporate funding enables university and hospital based research to occur while Health Canada facilitates this innovation by hosting international

¹⁹⁰ Media coverage of the "miracle" transplant of a forearm and hand was the same as the first transplant in 1967: medical miracle, surgeons as heroes, interest in the "success" of the transplant. Ian Phillips, *Globe and Mail* Friday, October 16, 1998. *op.cit.*

¹⁹¹ Steve Farrar and Dipesh Gadher "Tongue transplants will help organ cancer victims speak: Face restoration comes a step closer" *Ottawa Citizen* January 24, 1999. A1.

¹⁹² Jonathan Leake "Neurosurgon predicts 'head transplants' in the next century: Surgery using high-tech 'brain-cooling' device could extend lifespan of quadriplegics" *Ottawa Citizen* August 29, 1999. A1.

¹⁹³ Note that both of these techniques continue to rely upon the natural resource body, valuing the female body more due to its gestation capability. The second method, known as xenotransplantation, which follows the sameness principle, was a subject of serious debate at the House of Commons Event in 1999.

¹⁹⁴ Franklin Hoke "Biotech Companies Set to Profit From Animal-Organ Transplants: But animal-rights advocates call cross-species transplantation unnecessary and decry the creation of animal commodities" *The Scientist* 9(20): 1,10-11, 1995. p. 10.

conferences and devoting efforts to develop new protocols to be ready for an application to approve a xenotransplant product.¹⁹⁵

The history, limitations and outcome each of these research pursuits, what drives demand, what other forms of treatment may be possible if pursued and who stands to profit from this particular therapeutic modality are dimensions contained in a 'black box'. Focused on the technical possibility, where the "spare" body parts come from and how they will be accessed and whether replacement alters personhood is irrelevant. Viability is presented as the only question of any importance. The effect is to create an unexamined demand for transplantation proclaimed to be the only way to treat organ-dying patients. Consequently, linkages to the monetary economy, organizational power and status of medical science, and, the quest for immortality "dangled before the eyes of an ever-expanding sick, ageing, and dying population" that drive demand evade questioning.¹⁹⁶

2.3.3 *Human Relations*

Creating chimeras salvaged one life from the demise of two. Thus, in addition to the alignment of corporate investment and state support, what enables transplantation is the presence and linking of patients in hospital, dying in different orders. A minimal effect of this *technology of health* is thus the paradox that saving life requires death. More specifically, a dependency was created whereby one set of dying patients needs another, the distinction between them based on death order. Human agency exercised by transplant surgeons established the direction of transfer. Since kidney, liver and heart specialists were the first to invest in this way of seeking to cure, which person dying became the chimera and which the natural resource was determined by the patient they principally served - patients in need of those organs. In cases where one of the "replaceable" organs is needed in two patients, which "person" had their life saved as a chimera was not always clear. In his autobiography, liver transplant surgeon Thomas

¹⁹⁵ See "Report of the National Forum on Xenotransplantation - Clinical, Ethical and Regulatory Issues" Therapeutic Products Programme, Health Canada, November, 1998 and "Report of the National Consensus Conference on Safety of Organs and Tissues for Transplantation," Health Canada, 1995.

¹⁹⁶ Nancy Scheper-Hughes "The New Cannibalism" *New Internationalist* . Issue 300, April 1998. pp. 14-17. p. 14.

Starlz reflects on how the direction of transfer in the 1963 case of a child named Bennie would have been debatable had Dr. Barnard demonstrated the heart replaceable five years earlier.

Bennie's donor was another child who died during an open heart operation. In looking back, one can ask why Bennie, who himself was on life support with a ventilator, should not have donated a heart to the other child instead of receiving his liver.¹⁹⁷

In most cases, however, early identification of the availability of patients dying brain-first along with the creation of 'brain death' as a type of death entrenched the place of this set of patients as the "givers."¹⁹⁸ Such was the case in Starlz's account of a patient named David Yomtoob, who was dying liver and brain-first due to an inherited disorder called Wilson's disease. According to the transplant surgeon:

It seemed too late. Or was it? Another child with a fatal brain injury lay in a bed thirty feet away. What could Yomtoob's mother do? She prayed to God for the life of both children, believing that there was no hope for either but knowing that the other patient already had been pronounced brain dead. That night, September 26, 1981, the second child's liver was used to replace that of her son, who turned back from shadows so deep that no one had been there before and returned.¹⁹⁹

The value of the second patient to the life of the first illustrates the 'double medical gaze' whereby the patient dying brain-first (at a faster speed in this case) was treated as an object for the first. In other cases, this *technology of health* leads parents to look for hope to save their own child by searching directly for 'potential donors' - reading newspapers for reports of violent deaths²⁰⁰ or finding out if there are any children on life support in the hospital.²⁰¹

¹⁹⁷ Thomas Starlz, 1992. *op.cit.* p. 99.

¹⁹⁸ Note that prior to 'brain death' criteria and in the 1990s using 'non-heart beating cadaver' protocols (discussed in chapters 3, 4 and 5), patients who die by cessation of breathing and heartbeat first qualify as 'potential donors'. As noted earlier, this occurred through the procedure of waiting a period after death was declared to then resume intervention to regenerate the organ for re-use. See also Renée C. Fox "Afterthoughts: Continuing Reflections on Organ Transplantation" Stuart J. Younger, Renée C. Fox and Laurence J. O'Connell 1996. *op.cit.*

¹⁹⁹ *Ibid.* p. 255. Note that the medical articles referenced with respect to this case refer to equitable allocation.

²⁰⁰ Victoria Poole, *Thursday's Child* Boston: Little, Brown and Company, 1980.

²⁰¹ Derek McNaughton, "In search of the gift of life," *Ottawa Citizen*, February 10, 1999. *op.cit.*

During the experimental era, the making of chimeras raised philosophical questions such as whether the patient remains “themselves” with part of someone else’s body. Chapter four shows how questions about identity in the face of hybridity were drowned out by a public discourse of donation whereby “the correct” rhetoric using a language of recipients and donors instead of chimeras and natural resources “is one of boundaries safely circumscribed.”²⁰² With respect to the demand for organs, diseases and death came to be defined in relation to specific organs; “fatal illness” re-classified as “end-stage organ failure” using mechanistic imagery to imply that an isolated part and not the whole are in the process of disintegration. Should full body transplants become possible, who the person is when the head of one is attached to the body of another may re-surface questions of identity while pointing out the significance of how death is defined in shaping priorities and categories critical to the practice of transplantation. Using ‘brain death’ as the definition of death, addressed in chapter three, the mind is given the locus of personhood and its functioning serves as the critical factor in distinguishing who becomes the chimera and who becomes the natural resource. In 1999, metaphysical and ontological questions regarding death and making new ‘kinds’ of bodies are overshadowed by the imperative to supply organs to “save life.”

2.4 Conclusion

Tracing how replacement from the ‘living dead’ as a way of seeking to cure became a therapeutic modality opens up the complexity and human agency contained in the first ‘black box’ of the transplant episteme. It was not a “discovery” that enabled replacement to become a possible way of seeking to cure, it was a series of ‘openings’, choices and the exercise of power in shaping the possible. As demonstrated, a particular combination of factors enabled the shift from accessing the dead to investing in live to live body part transfers to accessing the ‘living dead’. Setting precedents and patterns that would be repeated, the conceptual separation of personhood from embodiment functioned as a critical tool of enrolment the medical lobby utilized to pressure

²⁰² Margaret Lock, 1995 “Transcending Mortality: Organ Transplants and the Practice of Contradictions” *Medical Anthropology Quarterly* 9 (3), 1995. p. 392. (390-399)

government to expand the categories deemed available within institutions. Slow concession to the demands of the medical profession and a fundamental change in attitude over one hundred and fifty years permitted the dissection of cadavers. Medicine expanded its domain into death through this movement and established the body as object. As a prelude to manipulation, the utilitarian use of the body for knowledge of anatomy “for the good of society” led to its use on the same basis for therapy.

Parts of bodies assumed a value to others as a result of investment in research to make body parts replaceable. Undermining the uniqueness of bodies as an aspect of individuality, the quest to hybridize followed the pattern of identifying sameness, suppressing difference and eventually inducing sameness. Treating patients through the transfer of blood, micro-parts and organs was therefore not in any way immanent. As demonstrated, this *technology of health* emerged from a concerted, and largely unsuccessful, effort to flatten bodily distinctions between unique genetic entities. This has been accomplished, instead of other options, as a choice of medical scientists and transplant surgeons within a research environment in which corporations make decisions based on profit, and the state supports new economic ventures. Vested interests with non-altruistic motives characteristic of the state-supported capitalist market dovetail the competition and prestige characteristic of the medical profession. As contributors to this therapeutic modality, both serve to propel the transplantation industry forward.

The history of this *technology of health* illustrates that knowledge of much more than the technical possibility to transplant is necessary to understand what drives this way of seeking to cure. Most important is the formation of an imperative to produce the chimeric body which creates the necessity to produce the natural resource body. Now that the ways in which the former is produced have been analyzed, this thesis turns to the latter. Addressed in the next two chapters are other aspects of the transplant episteme focused on the natural resource body. This includes how the strive for immortality inherent in “the clinical dream of the totally replaceable body” is concealed by the adjustments to accommodate this means of seeking to cure.²⁰³

²⁰³ Alonzo L. Plough, *op.cit.*, p. 5.

Chapter Three The Construction of Authoritative Knowledge

To treat patients by replacing body parts other than paired organs, a supply of “spare parts” was necessary. In December 1967, South Africa’s Dr. Christiaan Barnard removed a healthy heart from 25 year old Denise Ann Darvall and placed it in the body of Louis Washkansky who died eighteen days later. This “world first” exposed to the public the progressive expansion of medical science from use of the dead for knowledge, to live-to-live transfers for treatment, to use of the ‘living dead’ for the treatment of others. Expansion of transplantation in the late 1960s to include non-paired, vital organs presented a serious problem: how could donors be dead when their removed body parts were alive? To the self/other boundary crossed by the very idea of organs as interchangeable was added a second conceptual challenge of crossing life/death boundaries. Treatment of heart disease by replacement thus required that the public permit the surgical removal and transfer of living parts from dying persons to replace dying parts of living persons.

In Japan, the first doctor to remove an organ prior to cessation of the entire body was arrested on charges of murder.²⁰⁴ Though eventually acquitted, societal attitudes and institutions in this country have refused to permit the procuring of organs from dying persons. As a consequence, body part replacements in Japan have remained restricted to kidneys from live donors. By contrast, public controversy in the West regarding the alive/dead status of the donor was countered by expressions of hopeful enthusiasm for a triumphant opportunity to “save human life.”²⁰⁵ Objections to the harvesting of organs from the ‘living dead’ faded away following the creation and widespread acceptance of the concept of ‘brain death.’ This chapter examines how this turn of events occurred to enable the dying to be used as a source of replaceable body parts in Canada.

²⁰⁴ Margaret Lock “Death in Technological Time: Locating the End of Meaningful Life” *Medical Anthropology Quarterly* 10(4): 575-600, 1996.

²⁰⁵ Honorable Francis B. Burch, Attorney General, State of Maryland, at the Maryland Symposium “Organ Transplantation – Current Medical and Medical-Legal Status: The Problems of An Opportunity” May 24, 1969. Sadler and Sadler, 1969. *op.cit.*

Using Rose's analytical category of *dividing practices* and actor-network theory's translation process, the argument made in this chapter is that the removal of vital organs from the 'living dead' was legitimated by making a stage of disintegration in the process of dying a visible category of 'non-person.' Following the primary division separating the chimeric body from the natural resource body, other *dividing practices* used to create the latter include: the separation of what falls within the domains of religion, medicine, the state and the law; the distinction between persons and non-persons made by a diagnosis; and administrative rules separating 'donor' and 'recipient' medical teams. Turning to the dead as a source of organs required an adjustment in the signs taken to indicate the end of the obligations accorded to persons. Shifting from waiting until the entire body stopped, to waiting until the heart stopped, to waiting until a number of neurological functions ceased in the process of disintegration was a weak and fragile idea in the late 1960s, hotly debated among surgeons. It transformed into a 'fact' through the release of a diagnosis for death and creation of the concept of 'brain death.' An absence of signs of life located in the brain as death is the truth claim the replacement of non-paired vital organs (all but the kidney) cannot do without. The concept of 'brain death' as the end of personhood thus functions as an 'obligatory point of passage' and the second 'black box' of the transplant episteme. By considering only its presence or absence, the controversies, complexity and normative commitment holding this fact in place are concealed. Power is contained in the adjustment of Reality through this truth to accommodate transplantation as a way of treating illness.

As this chapter will illustrate, instilling widespread physician application of a *dividing practice* separating the 'brain dead' as non-persons from persons and achieving widespread enrolment in seeing the 'brain dead' as 'non-persons' came about through the continual refinement of the diagnosis and hegemony of medicine. Use of scientific methods to legitimize truth displaced questions of meaning with debates on technical aspects of brain activity. Leaders of the Christian religion conceded to this by deferring knowledge of death to medical professionals. Legal authorities aligned with the new death by seeing a need for a rule regarding the natural resource/donor patient that facilitated transplantation only by consequence.

I argue that as a “temporary expression of knowledge/power,” the classification ‘brain death’ semantically and in practice bridges two understandings of the end of personhood: as an event and as a process.²⁰⁶ By qualifying part of the body as dead, a process of disintegration is implied while the term dead signifies a moment of time at which life is over. If the same state was called ‘body alive’, it would imply the inverse: that a person is still present. Instances in which a distinction is made between the ‘brain dead’ and the ‘dead’ expose that the ‘body alive’ interpretation holds when the question of burial arises. Such moments reveal that ‘brain death’ is not synonymous with ‘death’. I agree with Margaret Lock that the significance of the judgement, based on the brain, is to say that “meaningful life” is over.²⁰⁷ Following the separation of personhood from embodiment established in gaining access to the dead for dissection, this thesis looks however specifically at personhood. The argument made here is therefore to examine the creation of the category itself to suggest that the purpose of the classification ‘brain dead’ is to mark a point at which the patient is alive enough to be useful but dead enough to use. I argue that the critical division made by application of the diagnosis is the absence of personhood.

This chapter follows ‘brain death’ as science-in-the-making in three parts. First is an account of the problem transplant surgeons saw in taking organs from dying persons and the weak and fragile idea proposed to resolve this dilemma. This section builds upon the work of medical anthropologist Margaret Lock by re-examining and adding to the original sources of the debate she identified among Western transplant surgeons.²⁰⁸ As an original contribution, the second section adds to this by tracing the inscription of the idea of ‘brain death’ as it becomes stronger and more resilient in Canada.

²⁰⁶ David Armstrong, 1994. *op.cit.* p. 17.

²⁰⁷ Margaret Lock, 1996 “Death in Technological Time,” 1996. *op.cit.*

²⁰⁸ *Ibid.* Lock draws upon the conference held by Dr. Barnard published by Hillel A. Shapiro (ed.) as *Experience with Human Heart Transplantation: Proceedings of the Cape Town Symposium, 13-16 July 1968*. Durban: Butterworths, 1969. From her work I returned to this source to draw upon it and another conference held in 1966 by the Ciba Foundation in London, England published by Gordon Wolstenholme and Maeve O'Connor (eds.) as *Law and Ethics of Transplantation, Ethics in Medical Progress*, London: J&A Churchill, 1968. A conference held in Maryland in 1969 (Sadler and Sadler) and consultations by churches in South Africa in 1972 (Oosthuizen) are other primary sources used in this chapter (see Appendix C).

3.1 What Came to Light

Prior to and alongside the development of replacement as a *technology of health*, several phenomena emerged to aid the attempt to gain access to the dying for organ harvesting. Most important, a prerequisite for all truth claims to be analyzed according to the methods, instruments, and standards of judgement utilized by the medical profession was exclusive domain over death.²⁰⁹ Taking a long view, Martin Pernick provides evidence to show how “the actual diagnosis of death was primarily a non-medical function” for most of Western history.²¹⁰

From antiquity to the sixteenth century, diagnosing death was not a responsibility of the doctor. Due to the prohibition of medical treatment for terminal patients under Hippocratic medical ethics, the role of classical and medieval physicians was to forecast an impending demise and then withdraw from the case... ‘Signs of death’ did not signal actual death; rather, they indicated when the doctor’s job was finished.

Medical professionals came to oversee and verify death in response to changes in medical practice starting around 1750. Primarily, this was through the process of gaining access to the dead for dissection. However, two other phenomena influenced the establishment of medical expertise as the sole expertise over death. First was the hygiene movement of the early nineteenth century. Putrifaction was at one point in time the only sign of death to which various authorities could agree. What changed this was the theory that bacteria from the dying caused epidemics. Thus arose the first instance in which waiting for the onset of death became a problem for the population.²¹¹ Between 1740 and 1850 the hygiene movement of public health workers instituted laws and conducted public campaigns as a *technology of health* requiring quick burial. Certifying death prior to burial became the role of medicine, done to speed up death rituals.

Second, medical techniques to resume breathing and heartbeat, the absence of which were previously interpreted as signs of death, brought knowledge of death into question. Faith in the ability to know death was undermined by the thought that the

²⁰⁹ Steven C. Ward “The Making of Serious Speech: A Social Theory of Professional Discourse” *Current Perspectives in Social Theory* 15:63-81.

²¹⁰ Martin S. Pernick, 1988. *op.cit.*

person could come back to life. Inspiring a “pre-mature burial panic,” death certificates issued by legal authorities were introduced to guard against burial prior to the end.²¹² As a result, religion and the law deferred to medical authority as the only expertise that could determine death with certainty. Thus, the medical profession became the exclusive authority judged able to determine actual death. Prior to 1968, death was conceptualized as an event marked by the cessation of the heart. Thus, a period of time after which repeated attempts to revive the heart failed was accepted as a point of death.

Viewing the death of the brain became possible with the installation of the electroencephalographic (EEG) machine in hospitals. Introduction of ‘life support’ machines in hospitals in the 1950s aided surgical procedures and resuscitation but had the effect of concealing the point at which efforts became futile. “Prolonging life” by applying “extraordinary efforts” became a topic of discussion in the late 1960 and 1970s with respect to patients on life support for extended periods of time and the heroic but usually failed attempts to treat patients by organ replacement.²¹³ From the outset, the official rationales for defining death were: cessation of treatment, and, the need to know when organs could be removed. As discussed below, the convergence of these two medical needs significantly aided the enrolment of the medical profession, the legal profession and society in the truth of ‘brain death’.

Within this context, two clear responses emerged from Dr. Barnard’s heart transplant as a conflict of interest between the life/death relationship of donor and recipient. On the organ-dying potential recipient side, the media in Europe and North America portrayed the surgeon as a hero and the event a medical miracle.²¹⁴ Concern focused on the success of the operation, measured by the length of time the recipient continued to live with someone else’s heart. A hope was sparked for the 80,000 patients under 65 in the United States alone who died of degenerative heart disease annually for which there was, at that time, no cure.²¹⁵ Over the course of the twentieth century, chronic disease had come to displace epidemics as a primary cause of death. Repeating

²¹¹ *Ibid.*

²¹² *Ibid.*

²¹³ Renée C. Fox and Judith P. Swazey, 1978. *op.cit.*

²¹⁴ Margaret Lock “Death in Technological Time,” 1996. *op.cit.* p. 581.

²¹⁵ Sadler and Sadler, 1969. *op.cit.* p. 18.

the moral impetus displayed at medicaid review hearings, some politicians and legal experts expressed enthusiasm in support of the possibility of chronic disease treatment. Stating that “no tribute to the courage and humanity of the pioneers can be too high,” this group sought to affiliate themselves with such valued members of society by embracing the opportunity to participate in transplantation.²¹⁶ To facilitate this therapeutic modality, it was argued that “jurists certainly must adapt their rigid, over-conceptualized thinking to the novel conditions” in order to permit this social good.²¹⁷

Over the months that followed, however, initial praise gave way to doubts and criticism. Barnard was accused of trying to play God and criticized for mistreating both recipient and donor. Common knowledge held that the mind and the soul resided in the heart, thus “to transplant such an organ from one person to another is inevitably the height of sacrilege.”²¹⁸ An article in the *Nation* reminded readers of “the forgotten half of the transplant equation,” the donor.²¹⁹ It stated that, “‘contrary to the general impression, few doctors can predict the so-called ‘moment of death’ with certainty’.” Noting that the need for donors will require the redefinition of death, the article asked, “when are you dead *enough* to be deprived of your heart?”²²⁰

Expanding the circle of patients susceptible to treatment by replacement to include those with non-paired vital organ diseases could not proceed without a source of organs. A 1966 remark that the “shortage of supply is already a major limitation” explains why physician-researcher teams initiated experiments to use animals as a source,²²¹ started taking kidneys from non-related dying persons and why finding a way to make the dead a source of organs was seen as necessary.²²² “One of the highest fatal road accident rates in the world and a high death rate among the poorer sections of the population from personal violence” was cited in South Africa in 1972 as the reason for

²¹⁶ David Daube “Transplantation: Acceptability of Procedures and the Required Legal Sanction” p. 200. Wolstenholme and O'Connor (eds.), 1968. *op.cit.*

²¹⁷ David Daube, 1968 *op.cit.*

²¹⁸ G.C. Oosthuizen *The Ethics of Tissue Transplantation* Cape Town: Howard Timmins. 1972. p. 21.

²¹⁹ Margaret Lock “Death in Technological Time,” 1996. *op.cit.*

²²⁰ *Ibid.*

²²¹ Thomas E. Starzl, 1992. *op.cit.* p. 68.

²²² M.F.A. Woodruff “Transplantation: The Clinical Problem” Gordon Wolstenholme and Maeve O'Connor (eds.) 1968 *op.cit.* p. 8.

the availability of patients dying brain-first.²²³ For technical reasons, young people who were otherwise in good health were targeted first by transplant surgeons as 'potential donors'.

Trauma to the head as a cause of death rose over the course of the twentieth century, as the automobile became a primary instrument of death.²²⁴ Sure enough, prior to her participation in the world's first heart transplant, it was an automobile crash that led to the admittance of 25 year-old Denise Ann Darval into an intensive care unit at a Cape Town hospital on December 13, 1967.²²⁵ Three years later official statistics for the United States showed that one third of deaths of young people between the ages of 15 and 24 were caused by motor vehicle crashes.²²⁶ In 1994 the cause of death by unintentional injury for Canadians (other than B.C. residents) was 59.7% by motor vehicle crash impacting the brain/skull.²²⁷ Homicide, suicide or sudden acute illness to the brain such as spontaneous cerebral haemorrhage or stroke also filled the set of patients first identified as possible donors.²²⁸ Access to this group provided treatment for one medical condition by capitalizing on another. The trouble in the late 1960s was not the prevalence of this group but the ability to declare them dead while their heart still beat and circulation flowed. Without formal rules but an understanding of death as the cessation of all bodily functions, the legitimacy of medical intervention harvesting vital organs was questionable unless the patient was considered already dead. Once the obligations of personhood ended by declaration of death, removing the beating heart while it was still alive enough to be useful to another could not be considered murder.

²²³ J. Alan M. White, Principal Surgeon, Addington Hospital, Durban "The Donor, The Transplantation Programme and the Moment of Death" G.C. Oosthuizen (ed.), *op.cit.*, 1972. p. 54.

²²⁴ Rick J. Carlson, "Business as Usual?" *Technology and the Quality of Health Care* Richard H. Egdahl and Paul M. Gertman (eds.) Germantown, Maryland: Aspen Systems Corporation, Boston University Health Policy Institute, 1978.

²²⁵ Lesley A. Sharp, 1995. *op.cit.* p. 358.

²²⁶ Rick J. Carlson, 1978. *op.cit.* p. 49.

²²⁷ Douglas E. Angus, Eden Cloutier, Terry Albert, Denis Chenard, Anita Shariatmadar *The Economic Burden of Unintentional Injury in Canada* Smartrisk Foundation, 1998. p. 25

²²⁸ Nora Machado *Using the Bodies of the Dead: Legal, ethical and organizational dimensions of organ transplantation* Aldershot: Dartmouth, 1998. p. 8.

3.2 A Weak and Fragile Idea

With growing medical interest and public attention, the use of the dying was one of several subjects of debate at conferences on transplantation held in 1966 and 1968, one year prior to and after the world first heart transplant. Although all participants had an interest in the expansion of this therapeutic modality, they did not agree on when in the process of physical disintegration the organs of a patient could be removed. Even the small group performing these operations did not agree on what signs indicated death, whether an official re-definition was necessary, what it should be and whether changing the signs of death from the heart to the brain would ever be accepted.

A 1966 conference held in London by the Ciba Foundation on ethics, medical progress and transplantation brought participants from the United Kingdom, Italy, Sweden, U.S.A., France, the Netherlands from the medical and legal profession, in addition to one member of the Christian clergy, to discuss how to reform the law to accommodate transplantation.²²⁹ The need for a steady supply of 'spare' organs was discussed several times by way of comparison to live-to-live kidney transplants and in anticipation of liver, lung and heart transplants becoming feasible. A preference was articulated for the use of dead rather than living non-related donors as a source for kidney replacements due to the ethical problem and medical risk of maiming a person for the sake of another. Joseph E. Murray argued that "the practical possibilities are limitless; progress is so rapid, the need so great, and interest so high that it would be rash to put any limits to future progress in organ transplantation."²³⁰ On this basis he estimated the annual availability of 10,600 kidneys and 6,000 livers from cadavers in the United States based on deaths from neurological conditions, if no legal or logistic problems existed.²³¹ The goal expressed was to "qualify the concept 'life' by saying that it requires the presence of mental functions."²³² Separating 'death,' as meaning that a person is

²²⁹ Gordon Wolstenholme and Maeve O'Connor, 1968. *op.cit.*

²³⁰ Joseph E. Murray, "Organ Transplantation: The Practical Possibilities" Gordon Wolstenholme and Maeve O'Connor (eds.) 1968 *op.cit.* p. 64.

²³¹ *Ibid.*

²³² G.B. Giertz "Ethical Problems in Medical Procedures in Sweden" p. 147. Gordon Wolstenholme and

spiritually dead, from cessation of the whole being allows what remains - regardless of its functioning - to be viewed exclusively from a biological and medical frame of reference.

Although it was noted that "the medical and psychological prospects [of cure] would be much better if incurable unconscious individuals were used as donors," all agreed that use of the living dead was desirable so long as it was "guaranteed that he is certified as really and positively dead."²³³ But Dr. Thomas Starlz warned of a moral problem,

...the new risk is introduced that the terminal care of such potential donors may be adversely influenced by the events which are expected to follow after death, which might conceivably remove whatever small chance there might have been for survival. Some people at this meeting support the view that, by use of the electroencephalogram (EEG) and a variety of other physiological measurements, death can be established from other physiological criteria than the absence of heart beat and cessation of respiration; on the basis of these criteria kidneys have already been removed in several centres when the donor had a good circulation. *Such a practice is advantageous for the recipient, who can thus be assured of receiving a better kidney*, but does this *pragmatic consideration* justify a legal redefinition of death, and if so, upon the basis of what infallible evidence?²³⁴

In response, Belgian surgeon G.P.J. Alexandre, who had already removed kidneys of nine dying patients, offered to the group the five conditions his team decided were suitable indicators of death before organs were removed. Technical points were debated on the basis of tests performed, physiological signs of life and period of time waited in case the 'potential donor' recovered. He argued that biologists accepted one minute of silence from a EEG machine testing for brain activity "as incontrovertible proof of death."²³⁵ Murray responded by saying, "Those criteria are excellent. This is the kind of formulation that we will need before we can approach the legal profession."²³⁶ As he tried to get "some bracket of time that we might agree on," after which point recovery was

Maeve O'Connor (eds.) 1968. *op.cit.*

²³³ G.B. Gieritz "Ethical problems in medical procedures in Sweden" p. 148 and R. Cortesini "Outlines of a Legislation on Transplantation" p. 185 Gordon Wolstenholme and Maeve O'Connor (eds.) 1968. *op.cit.*

²³⁴ Joseph E. Murray, 1968. *op.cit.* p. 67. (emphasis added) In his autobiography, Dr. Starlz wrote that he later reversed his view once safeguard protocols were introduced.

²³⁵ Gordon Wolstenholme and Maeve O'Connor (eds.) 1968. *op.cit.* p. 68.

²³⁶ *Ibid.* p. 69.

impossible and organs could therefore be removed, Starlz interrupted by asking whether it was even possible to define death based on the brain rather than the heart.

Would our agreement on such definitions have any validity? I doubt if any of the members of our transplantation team could accept a person as being dead as long as there was a heart beat...Would any physician be willing to remove an unpaired vital organ before circulation had stopped?²³⁷

To this the surgeon from Lyon responded positively by adding two additional criteria to Alexandre's while the surgeon from Edinburgh told of a code of rules developed in France to issue death certificates for persons kept alive by artificial means. Surgeon Roy Calne interrupted this exchange to express a second dissenting view.

But the point that is important is whether this is being done because one is looking for a kidney rather than because it is in the interests of the patient who is dying...Although Dr. Alexandre's criteria are medically persuasive, according to traditional definitions of death he is in fact removing kidneys from *live* donors. I feel that if a patient has a heart beat he cannot be regarded as a cadaver...Dr. Hume, who has a large and successful experience of cadaver transplantation, does not start to remove the kidney until the heart has stopped beating...Any modification of the means of diagnosing death to facilitate transplantation will cause the whole procedure to fall into disrepute with the rest of the profession.²³⁸

American G.E. Schreiner added a comment that neither administrative separation of the two medical teams nor professional reputation are germane to the philosophical problem. As the discussion moved on to Dr. Starlz's use of prisoners as a source of kidneys, it was clear that the answer to the dilemma of death - that some would act on - was to establish a set of rules to allow parts of the body to be removed while other parts remained alive.²³⁹ While no consensus was arrived at the London meeting, Dr. Schreiner's earlier remark carried the day:

...there ought to be a mechanism for collecting affidavits from all the scientists qualified to speak to this point with authority, so that a medical definition of death can be reached which would, in effect, have legal force. Then if law and society

²³⁷ *Ibid.* p. 70.

²³⁸ *Ibid.* p. 73. (emphasis added)

²³⁹ J.E. Murray, 1992. *op.cit.*

brush aside some of the archaic rules concerning anatomy, it seems to me that the whole ground-work will be laid for cadaver transplants.²⁴⁰

Dr. Calne's view that the cessation of the heart should and could remain the sign of death did not receive support. He shared concerns with Dr. Starlz that a conflict of interest was introduced when the source of cure was another patient but stated that this could be managed by an administrative rule.

A final discussion at the conference concluded by repeating the theme of rationality that transplantation must continue. "As our thinking about transplantation of human organs develops, people must become enlightened enough not to think of this as a horrible experiment, or indeed as an experiment at all, but learn to accept it as a normal event."²⁴¹ From the perspective of surgeons, there was already too much invested in transplantation for abandonment; objection would have to become accommodation.

Two years later - and half a year after the world first heart transplant - the normative commitment of transplant surgeons was made obvious at a conference held by Dr. Barnard in July, 1968. At "The Cape Town Symposium" on human heart transplantation, a collection of 12 surgeons conducting experiments in transplantation gathered to share information on surgical and selection aspects of harvesting and transplanting body parts. Dr. Barnard made it clear at this event that "his prime interest was in the condition of the donor's heart rather than in the condition of the donor as an individual."²⁴² Nonetheless, neurosurgeon Dr. de Villiers was called upon to describe when a patient could be thought of as a 'potential donor'. Discussion at this forum repeated the exact concerns of the 1966 Ciba Foundation group. Problematic was the "conventional point of death," whereby cessation of the heart beat was the earliest possible moment to declare death. Since this made it impossible to carry out the "proper preparation" of a heart for transplant, it was necessary to redefine death based on the brain.

Debate centred upon fixing death to a precise moment: at a point early enough that the heart is still beating but after the point at which a clinical decision is made to stop

²⁴⁰ Gordon Wolstenholme and Maeve O'Connor (eds.) 1968. *op.cit.* p. 68.

²⁴¹ *Ibid.* p. 211.

²⁴² Margaret Lock "Death in Technological Time," 1996. *op.cit.* p. 581.

treatment. But not everyone agreed. De Villers stated that " 'for social and legal reasons' the introduction of 'radically new concepts' with respect to death should be avoided."²⁴³ A surgeon named Rose-Innes argued that the responsibility for deciding when to terminate treatment should be entirely "a technical medical decision" free from the consent of relatives or legal authority.²⁴⁴ Termination of treatment was not, however, the "death point" in his view. Death was the cessation of the central nervous system that occurs 5-15 minutes after the cessation of the heart and lungs. Thus the conventional point of death when the heart stops was for him an occurrence prior to actual death.²⁴⁵ Kantrowitz, an American transplant surgeon, suggested that the "irreversible brain death" be the "point" at which treatment is terminated. Dr. Cooley, a U.S. transplant surgeon responded to this exchange by saying that it was the recipient who must be uppermost in the doctor's mind. He gave the group a warning:

Neuro-surgical colleagues at times have used terms which should be avoided. In the first place - I think that we should avoid the words 'alive' and 'dead' as synonymous with brain function or cardiac function. 'Alive' and 'dead' are such nebulous and vague terms, so ill-defined that they will never be defined, since no one understands either the meaning of 'life' or 'death.' One should say the heart is contracting, or beating, but not 'alive'... And I am sure that each of us is honest enough to admit that the heart was still contracting... when it was used in the actual operation. Brain destruction was irreversible in all instances.

In my opinion the clinician can become too pre-occupied with the rights of the dead, namely the donor, at the expense of the recipient. We should not jeopardize the possible survival of the recipient while we are waiting around to make a decision whether the cadaver, as you call it, is dead or not.²⁴⁶

All present sought ways to alleviate the suffering of their patients who were dying organ-first due to chronic illness. Working on behalf of organ-dying potential recipients, the possibility of cure trumped all other concerns. Dr. Barnard reinforced Dr. Cooley's position by declaring:

On the whole, people will agree that there is no need to wait for conventional death. Dr. Rose-Innes said that one should wait until that point, because only at that point can one say with certainty, after a certain period, that the patient will be dead -- is

²⁴³ *Ibid.* p. 582.

²⁴⁴ From Hillel Shapiro, 1969. *op.cit.* quoted in *Ibid.*

²⁴⁵ *Ibid.*

²⁴⁶ *Ibid.*

that correct? But I can tell you that if you have a patient with or who can fulfil the criteria for becoming a potential donor, once you stop the respirator you can also be certain that the patient will die, so why wait until the heart stops beating when you are sure that the patient is going to die?

Rose-Innes retorted that the patient must be declared dead before the transplant surgeon could proceed while another surgeon exclaimed, “ ‘we don’t even have a definition of death’.”²⁴⁷ Dr. Barnard remained unconcerned. Other suggestions that the termination of treatment be the responsibility of neurosurgeons rather than transplant surgeons or that formalized criteria for death be developed were dismissed by Barnard and Kantrowitz. In their opinion, a fixed definition was not necessary, because the medical profession “has always demonstrated that it could be relied upon,” and “people, ‘around the world’ have confidence in physicians.”²⁴⁸ Nonetheless, before the end of that year, death was officially defined for the first time in a way that facilitated organ transplantation. Discussion among transplant surgeons regarding the death of the donor was thereby set aside.

Debate over when organs could legitimately be removed at both conferences was marked by a conflict of needs between two sets of dying patients: those dying brain-first, who may or may not be or remain alive, and those dying organ-first who will die unless the first group can be cannibalized. With the objective to treat the second set of patients, three positions emerged as sufficient to justify the surgical process of amputation and organ removal: the prognostication that a patient will die, that death is consistent with signs of life and/or that knowledge of death based on cerebral function is infallible. Separation of physicians and a terminology of old and new were *dividing practices* added by some participants as conditions to the three positions to ensure the first set of patients, “the irreversibly dying,” are not compromised for the second set, “the reversibly dying.”

²⁴⁷ *Ibid.*

²⁴⁸ Margaret Lock “Death in Technological Time,” 1996. *op.cit.* p. 583.

3.3 Aligning Medicine: Formal Diagnosis

A need to formally legitimize organ harvesting may have become more imperative in places such as the United States where law suits and negative public reaction threatened the liability of physicians taking organs from the dying. A law suit was filed in 1968 against physicians who violated the explicit refusal of authorization by next of kin to take the heart of Bruce Tucker for the seventeenth heart transplant performed in the world.²⁴⁹ An editorial in the *Journal of the American Medical Association* that year similarly warned that removing organs before death could be considered murder.²⁵⁰

Initiating a process that could lead to facticity, an Ad Hoc Committee of Harvard Medical School published "A Definition of Irreversible Coma" in the *Journal of the American Medical Association* in 1968.²⁵¹ In offering an unprecedented diagnosis for declaring the end of personhood, the committee declared that 'irreversible coma' could substitute for the cessation of vital functions as a sign of death. Two reasons were offered to justify a definition based on brain function. First, the burden on families, hospitals and those in need of beds was too great to defend the continued use of resuscitative/supportive machines to save patients whose hearts may still be beating but who suffered irreversible brain damage. This was especially the case given the limited success of these efforts. Second, " 'obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation'."²⁵² Application of the diagnosis required adhering to two principles: that a decision to declare 'irreversible coma' be made by one or more physicians directly involved in the case, and that the decision be strictly medical, not to be shared with any other authority. Families must be excluded from decision-making, "for their own sake" and religion plays no role by virtue of their

²⁴⁹ Law Reform Commission of Canada (LRC) "Criteria for the Determination of Death" Working Paper 23, 1979. p. 21.

²⁵⁰ Margaret Lock "Death in Technological Time," 1996. *op.cit.*

²⁵¹ Ad Hoc Committee of Harvard Medical School "A Definition of Irreversible Coma." *Journal of the American Medical Association* 205:337-340, 1968.

²⁵² *Ibid.* p. 337, quoted in Margaret Lock "Death in Technological Time," 1996. *op.cit.* p. 584.

own deference of expertise to medicine.²⁵³ The preface to the criterion makes the second point by stating that in 1957, Pope Pius XII conceded that – contrary to the beginning of life – it was “ ‘not within the competence of the Church’ to determine death in cases where there is overwhelming brain damage.” Verification of death “can be determined ‘if at all’ only by a physician.”²⁵⁴ Elsewhere medical personage have drawn on a 1966 document by the same Pope defining death as the departure of the spirit from the body marked by cessation of brain function rather than loss of heart-beat.²⁵⁵ This theological change facilitated acceptance of ‘brain death’ for Christians by naming the head as the point in the body where the soul resides. Thus in 1968, a “radical new concept” of death – shifting from heart to brain – was officially declared in North America.

Ensuring that the idea of brain-first death did not disappear into insignificance, a second organizations of high social status, the World Medical Association, quickly repeated the Harvard diagnosis by issuing a “Statement of Death” based on the brain in August of 1968.²⁵⁶ Nonetheless, from this point forward each country followed a different path. For instance, Margaret Lock has shown how the redefinition of death did not take place in Japan.²⁵⁷ Due to an ontological view of death as primarily a social event, “the biological and cognitive status of the patient is assigned secondary importance” by the majority, including clinicians.²⁵⁸ This contributed to a refusal to reduce death to a scientifically measureable point in time the truth of which could be known by ‘death tests’ based on the brain. A topic of public discussion for the next thirty years, Lock points to cultural views and social relations of death as reasons underlying resistance to concede death to the exclusive domain of medicine. Mitigating against medical access to the dying are factors such as the presence of a large number of family members observing

²⁵³ *Ibid.*

²⁵⁴ *Ibid.*

²⁵⁵ Thomas E. Starzl, 1992. *op.cit.* p. 149.

²⁵⁶ The World Medical Association “Declaration of Sydney Statement on Death” Adopted by the 22nd World Medical Assembly, Sidney, Australia, August 1968 and amended by the 35th World Medical Assembly, Venice, Italy, October 1983.

²⁵⁷ Margaret Lock “Death in Technological Time,” 1996. *op.cit.*; See also by the same author. “Reaching Consensus About Death: Heart Transplants and Cultural Identity in Japan” *Society* 13(1): 15-26, 1989; “Transcending Mortality: Organ Transplants and the Practice of Contradictions” *Medical Anthropology Quarterly* 9: 390-399, 1995; “Contesting the Natural in Japan: Moral Dilemmas and Technologies of Dying” *Culture, Medicine and Psychiatry*, 19: 1-38, 1995.

²⁵⁸ Margaret Lock, “Death in Technological Time,” 1996. *op.cit.* p. 577.

the process of death in hospital, location of the soul in the thorax and Buddhist death rituals that conceptualize the spirit remaining in this world 49 days after death so that there is never "a cadaver."²⁵⁹ As well, the idea of "personhood," as the "core" of humanity and individuality, is in this place more closely associated with the biological organism than located - following the Cartesian mind/body split - in the mind.

In the West, the Canadian Medical Association (CMA) followed the World Medical Association in releasing their own statement on death three months later. Deleted in each repetition of the statement were modalities of time, authorship and context. Social support by authoritative institutions in the West thus immediately pushed the statement towards facticity. Counting 177 articles and legislation in the United States as examples, a 1984 article mused that the Harvard medical school statement "likely spawned more medico-legal discussion and action than any other publication."²⁶⁰ Even critical responses took the Harvard Committee report seriously. As only individual voices of dissent, those who disagreed in North America were drowned out by institutional and cultural representatives of scientific reason.

Immediate use of 'irreversible coma' by up-and-coming transplant surgeons such as Dr. Thomas Starlz in the United States was an even more powerful endorsement. In his opinion, the "acceptance of brain death in 1968 was a boon to transplantation."²⁶¹ He attributed this term to Guy Alexandre of Louvain, who used it to describe the removal of kidneys from 'heart-beating' cadavers at the London 1966 meeting.²⁶² As cessation of brain function was legitimized as a sign of death, physician-researchers stopped waiting for cessation of the heart to remove organs.

Rather than trying to maintain a strong heartbeat and good circulation in the cadaver donors, the legal requirement before the end of 1968 was the opposite. Because all such donors were incapable of breathing if the brain actually had been destroyed, they were supported by ventilators. The steps to donation began with disconnection of the ventilator, which the public called 'pulling the plug'. During

²⁵⁹ Margaret Lock, "Reaching Consensus About Death," 1989. *op.cit.* p. 19.

²⁶⁰ Robert J. Joynt "A New Look at Death" *Journal of the American Medical Association* 252(5): 680-682, 1984. p. 682.

²⁶¹ Thomas E. Starzl, 1992. *op.cit.* p. 150.

²⁶² Starzl stated that "Isolated examples of this practice in other European countries were reported. At first this idea appalled me because I envisioned that the care of a trauma victim could be jeopardized by virtue of his or her candidacy to become an organ donor. These fears were unfounded..." *Ibid.* p. 147.

the five to ten minutes before the heart stopped and death was pronounced, the organs to be transplanted were variably damaged by oxygen starvation and the gradually failing and ultimately absent circulation.²⁶³

With a degree of protection from legal charges that they were causing death, replacement therapy found a source - and a more 'live' source - which they could use to expand treatment to non-paired vital organ diseases of the liver, heart and lungs. Chapter four shows how a discourse of donation mobilizing public and medical professional participation in transplantation contributes to 'black boxing' 'brain death'. In addition to the justification of "organ donation" as moral, treating the donor's death as unproblematic relies on the strength of a legitimating network of truth upholding the concept. The strength of medical and legal alignment to 'brain death' varies between Canada and the United States. While both resort to science to establish an absolute on technical grounds, this death is less durable in Canada due to an absence of legislation.

3.3.1 *The Canadian Story*

Creating the 'brain dead' as a visible category of 'non-persons' within Canada illustrates the translation process of actor-network theory. Although they overlap temporally, the medical and legal process of arriving at 'brain death' as 'fact' is examined in this section. Taking each in turn illustrates a shared recourse to science to resolve a problem influenced by different needs. I argue that identifying the end was an urgent matter for medicine as an indication of when medical intervention for another patient could begin. Legal authority, by contrast, emphasized the need to know the end in order to mark a point at which medical intervention could be entirely withdrawn. In spite of different motivations, I suggest that both authorities shared a paternalistic concern to conceal the social constructedness of redefining death by downplaying the subjectivity involved in observing signs of life. For medical practitioners this is evident in standardization of the diagnosis to minimize clinical judgement, whereas legal experts look to and elevate the scientificness of medicine as a way of solving uncertainty. As well, while facilitating replacement as a *technology of health*, both professions seek to

²⁶³ *Ibid.* p. 148.

separate the mixing of two patients implicit therein by establishing a rule to divide physician labour between the two (or more) patients involved.

In a series of diagnostic protocols released by the CMA from 1968 to 1998, 'death tests' become increasingly specific and time periods to ensure cessation of the brain fade away as application of the diagnosis increases due to the routinization of transplantation throughout the 1980s. The first of these was a "Statement on Death" publicized at a press conference in November 1968. Formulated by a Special Committee on the Definition of Death and approved by the Executive Committee, cerebral function was used to define death.²⁶⁴ Without using the term, this document endorsed the Ad Hoc Committee of the Harvard Medical School's position that 'irreversible coma' could be taken as a sufficient sign of death. Exerting exclusive expertise, the first point made repeats the World Medical Association document: that the determination of death is and should remain the legal responsibility of physicians.²⁶⁵ Two modern practices are cited as reasons for issuing criteria for death. First is the ability to maintain by machines the circulation of blood "through tissues of the body which may have been irreversibly injured," and second, "the use of cadaver organs such as heart or kidneys for transplantation."²⁶⁶ Noted as troublesome to establishing a precise definition of death is the observation that dying is not an event but a process:

A complication is that death is a gradual process at the cellular level with tissues varying in their ability to withstand deprivation of oxygen. But clinical interest lies not in the state of preservation of isolated cells but in the fate of a person. Here the point of death of the different cells and organs is not so important as the certainty that the process has become irreversible by whatever techniques of resuscitation that may be employed.²⁶⁷

Personhood is thus distinct from the body, not the same thing. As well, it is not cessation of the body but reaching a "point of no return" that counts. Repeating the Harvard document, aids to be used by clinicians to determine *irreversibility as death* are

²⁶⁴ *Canadian Medical Association Journal* "The Canadian Medical Association Statement on Death, November 1968," Vol. 99, December 28, 1968, p. 1266.

²⁶⁵ The World Medical Association "Declaration of Sydney Statement on Death," 1968. *op.cit.*

²⁶⁶ *Canadian Medical Association Journal* "The Canadian Medical Association Statement on Death, November 1968," *op.cit.*

²⁶⁷ *Ibid.* (emphasis added)

unresponsivity, no movements or breathing, reflexes and electro-cardio silence confirmed by an electroencephalographic (EEG) machine. Unlike the World Medical Association declaration, the CMA protocol states that determination of the death of the person makes it ethically permissible to remove organs from “the cadaver” rather than “to cease attempts at resuscitation.”²⁶⁸ It is added that if organ removal is the case, the decision that death exists should be made by two or more physicians without immediate concern with the performance of the transplantation.

Six years later, a far more prudent definition of death was passed as a resolution at the 107th Annual General Meeting of the CMA held in Toronto in June 1974. Indicating that irreversibility of vegetative states may not have been as straightforward as first thought, it is made clear that for patients suffering from coma, “great caution must be exercised before making a diagnosis of brain death.”²⁶⁹ Other significant changes include: extending rules on the separation of physicians attending the donor and recipient, mandatory knowledge of the underlying pathology and time delays required to ensure that spontaneous respiration (four minutes) and spontaneous movement (one hour) do not resume. Clarifying the separation of personhood from embodiment, a distinction is made between bodily movements based on origin: only reflexes mediated through the brain count as signs of life. Thus, “when spinal reflexes are preserved, peripheral stimulation may elicit movements, but must not elicit vocalization or facial grimacing.”²⁷⁰ Spinal cord reflexes are consistent with ‘brain death’; brainstem, thalamus or cerebral cortex responses are not. Further, the absence of signs of life must be deemed “irreparable with the presently available means,” implying that this could change. At the annual meeting a year later, two minor changes were made: that “brain” replace “mind” and the absence of a condition be modified. At both events, resolutions defining death passed without contestation, unlike euthenasia and abortion. Declaring when life begins, when death is chosen or when to stop resuscitation efforts without transplantation gave cause for debate; by contrast, the definition of death for organ removal did not.

²⁶⁸ *Ibid.* The only change to exact replication of the WHO “Declaration of Sydney Statement on Death” was dropping the clause indicating what determining the point of death makes it ethically permissible.

²⁶⁹ *Proceedings of the 107th Annual Meeting Including the Transactions of the General Council*, Toronto, June 24, 25, 26, 1974. CMA, Ottawa, 1974: 81-83.

²⁷⁰ *Ibid.*

At the 119th Annual General Meeting of the CMA in 1986, it was noted that the Association had received letters from transplant units questioning the validity and timelessness of the 1975 position.²⁷¹ Now that many hospitals had organ replacement programs, deficiencies were found in the death diagnosis. Seeking advice “particularly from those actively involved in transplant procedures,” a formal policy statement entitled “Guidelines for the diagnosis of brain death” was released in 1987 reflecting the 1986 resolution prepared by a subcommittee of the Canadian Congress of Neurological Sciences.²⁷²

Mobilizing brain specialists as the appropriate experts to declare the moment of death, amendments to the previous statement included stipulations that physician experience was required, precise time periods for testing for responses were dropped and precautions for a greater number of recovery possibilities were included. Re-evaluation was considered essential over an interval of 2 to 25 hours to reduce the possibility of observer error. Excluded from this diagnosis were infants and children who could not be sure to be brain dead due to insufficient study. Resorting to increasingly serious speech to resolve the potential cognitive dissonance of declaring a mobile patient “dead,” the criterion states that “confusing unusual spontaneous movements of limbs and trunk owing to spinal-cord reflex rather than cerebral function was to be avoided.”²⁷³ To enforce application of the criterion, it was recommended that hospitals adopt guidelines as the Medical Association policy statements possess no legal authority.

In 1998, the 1987 CMA guidelines were rescinded as part of a standard ten year review on the basis that they were out of date. Clinical practice guidelines issued by the Canadian Neurocritical Care Group in 1999 were offered as sufficient without endorsement by the CMA. ‘Brain death’ was also a topic shifted at that time from the ethics sub-committee to the health care and promotion sub-committee within the Association. Although the 1987 document is cited as the accepted medical standard for determining ‘brain death’ and is replicated significantly, the neurocritical care group guidelines make important changes.²⁷⁴ Most notable is the possibility for diagnosing

²⁷¹ *Proceedings of the 119th Annual Meeting 1986*, Resolution #86-69. CMA, Ottawa, 1986.

²⁷² *Ibid.*

²⁷³ *Ibid.*

²⁷⁴ Canadian Neurocritical Care Group (Canadian Neurological Society, the Canadian Neurosurgical

'brain death' in children. Indicating priority and resources dedicated to extending the diagnosis had taken place over the course of the decade, it was now only infants under two months of age (including "preterm infants") who could not be 'brain dead'. All other children qualified, with the provision that extra tests be performed at set time intervals for confirmation. The guidelines also describe the acceptable limits of several laboratory tests that can confirm 'brain death' on the basis of brain perfusion. Conditions that "may mimic brain death" are noted as is the fact that organ removal from 'brain dead' donors "is a separate issue." Unlike previous references to spontaneous movement, this version only states that "various spinal reflexes may persist in brain death."²⁷⁵

Exerting the form of legitimacy attendant to the medical profession, the idea of using the dying as a source of organs was translated into a strong association of truth. This network managed controversy by further refinement rather than abandonment of the concept. Making 'brain death' durable and transportable, modalities indicating the potential uniqueness of every case were deleted by increasingly technical language. Winning over dominant views within the profession meant that their authority could be used to mobilize 'action at a distance', as common practitioners took up widespread application of the diagnosis as a means to arrive at verifiable death. Disagreement with this diagnosis on any grounds became increasingly difficult as greater resources and allies formed in support of 'brain death' as fact. The effect of re-interpreting signs of life exclusive of questions of meaning by technical talk was to detach personhood from embodiment beyond the brain. 'Brain death' was either accurately diagnosed or not.

3.4 Legal Alignment

Unlike the experience in Japan, legal authorities in the West acted actively or passively to support a replacement *technology of health* by allowing for the creation of a source of spare parts. Although this came about through endorsing the truth claim that 'brain death' is death, parallel to the medical profession, in the absence of legislation in

Society, the Canadian Association of Child Neurology and the Canadian Society of Clinical Neurophysiologists) "Guidelines for the Diagnosis of Brain Death" *Canadian Journal of Neurological Science* Vol. 26: 64-66, 1999.

²⁷⁵ *Ibid.*

Canada (unlike the United States), the law is passive on when a person can be considered dead. While medical professionals have never been arrested and were supported in the only attempt made to claim they caused death by harvesting organs, recommendations to enshrine a definition of death in the law were ignored.

As opposed to medical statements, legal documents, detailed below, provide evidence to show that a different problematization operated to enrol legal experts in this particular network of truth. For medicine it was the need for a source from which to procure replacement organs. Marking the end point functioned to mark a starting point where intervening in the body for another patient was permissible. By contrast, Canada's Law Reform Commission and the President's Commission in the United States responded to medical "progress," exclusively in response to the need for an end point. They made clear that endorsing the idea that cessation of brain could be a sign of death responded to the 'cyborg situation' rather than the need for organs. Legal work aimed to provide physicians with a basis for withdrawing intervention in cases where a prolonged coma made the point of death unclear. It was only as an outgrowth of this goal that the definition - based on brain function - also facilitated transplantation. Permitting a category of 'non-persons' to become visible in law was thus arrived at by consequence.

Addressed in chapter four, active legal support of harvesting from the 'living dead' came through *Gift Act* legislation expanding the reason for "donating" the body at death from experiment to therapy. In instituting this quick endorsement, the question of when or what constituted death was not addressed. As expressed at the early transplantation conferences, whether legislation defining death by set criteria was necessary or helpful was a matter of debate. In the state of Maryland,

A report of the Subcommittee on the Definition of Death was unanimously adopted by the full Commission. That report concluded that it was unique to include criteria of death in a statute at this time, since *the question was primarily one of medical judgment* and since the state of medical knowledge was changing rapidly. It was realized that specific statutory criteria might soon become out of date and could impede further medical progress.²⁷⁶

²⁷⁶ Honorable Francis B. Burch, Keynote Address at the Maryland Symposium, Sadler and Sadler, 1969. *op.cit.* p. 68. (emphasis added)

Nonetheless, by legislating that vital organs could be removed from the dead with the knowledge that this would be futile if the organ was dead, “Gift” legislation complicitly endorsed the possibility that dying patients could be declared dead/ ‘non-persons’ at a point prior to cessation of the whole body. Whether the motivation to introduce this legislation was either to facilitate this *technology of health* or protect citizens from the possibility of commodification in parts that transplantation introduced, its consequence was to endorse the position that it was possible to be alive and dead at the same time. The enthusiasm expressed for the opportunity to save life through transplantation along with the faith in the goodwill of physicians expressed by politicians in Maryland suggest that at least in that state, the implicit re-definition of the end of personhood was done in order to facilitate the new possibility of cure.²⁷⁷ Legislation to protect donors from being declared dead/ ‘non-persons’ inappropriately was not considered necessary, nor a matter that fell within the legal domain.

Opposite to the position taken by Maryland, the state of Kansas passed legislation in 1970 declaring death by brain function. In 1975, the province of Manitoba followed suit by amending the *Vital Statistics Act* to state that “the death of a person takes place at the time at which irreversible cessation of all that person’s brain function occurs.”²⁷⁸ However, as described below, the introduction of a statutory definition of death based on the brain stopped here in Canada in spite of requests and recommendations to the contrary.

A case before the Manitoba provincial court of appeal in 1976 resulted in passive legal endorsement of ‘brain death’ as well as the view that removal of organs could be trusted to the medical profession.²⁷⁹ This case involved an attempt to appeal a conviction of manslaughter on the basis that organ removal caused death rather than the actions of a party in contact with the victim prior to hospital admittance. Seeking to deny the parties an opening to relinquish their causal responsibility in the death of a person required inadvertently supporting the position that the patient was already dead when organs were

²⁷⁷ *Ibid.*

²⁷⁸ *The Vital Statistics Act*, S.M. 1975, c. 5.

²⁷⁹ *R. vs. Kitching* [Man.] [1976] 6 W.W.R. 697, 32 C.C.C. (2d) 159 (Man. C.A.); *R. vs Green* (1988), 43 C.C.C. (3d) 413 (B.C.S.C.)

removed.²⁸⁰ This was a challenge since staff at the Health Sciences Centre in Winnipeg had failed to follow the Harvard criteria and certified the victim dead after, not before, his kidneys were removed. This meant that, "by traditional criteria, there is no question that Mr. Junor was alive when his kidneys were removed."²⁸¹ Nonetheless, in declaring the organ removal irrelevant since the patient "could not have lasted," the judge suggested that the medical staff were not guilty of improper conduct. No counter suit was laid following this case endorsing the judge's view that the profession could be trusted to regulate itself through the Colleges of Physicians and Surgeons.

An apathetic position on the question of death is apparent in measuring the response of legislators to recommendations of Law Reform Commission of Canada (LRC). Instances of legal difficulties raised by the problem of establishing the time or cause of death prompted the LRC to release a working paper on the topic in 1979. Of concern to the Commission was the problem of the criteria to determine death for two phenomena: withdrawing life support and removing organs. However, it was only the former that was seen to provide sufficient rationale for defining death. Repeated in all three LRC documents on the definition of death is a clear statement that, "the proposed legislation must not determine the criteria of death by reference only or mainly to the practice of organ transplantation."²⁸²

The first document was produced as a working paper of a Protection of Life Project which began in 1976. In it the Commission held the view that although practical tests and scientific diagnosis are relevant, medicine does "not have a monopoly in determining the normative concepts of death and thereby relevant policy."²⁸³ Further, it is unrealistic to believe that the public, despite its trust in the medical profession, should be willing to unquestioningly accept their criteria for death. Unlike the medical profession, it is legislators' responsibility to "recognize ethically, philosophically and socially

²⁸⁰ *Ibid.*

²⁸¹ There is no mention of a request of next of kin which may indicate use of *Anatomy Act* provisions granting permission of access to unclaimed bodies.

²⁸² LRC "Criteria for the Determination of Death" Working Paper 23, 1979 p. 56; LRC "Report on the Criteria for the Determination of Death," Report 15, 1981; LRC "Procurement and Transfer of Human Tissues and Organs," Working Paper 66, 1992. p. 176.

²⁸³ Jim Garner "Commission says criteria for determination of death not a purely medical decision, urges legislation" *Canadian Medical Association Journal* Vol. 121, August 18, 1979. p. 469.

acceptable standards.”²⁸⁴ Physicians then translate those standards into criteria. This set of legal experts were not prepared to concede determination of death to medicine. It was the role of the law to state a moment of death.

Thus, following consultation with interested parties, the Commission wrote a “Report to the Canadian Parliament” in 1981 recommending legislation defining death based on brain function. In taking this position, the Commission sought to make explicit what “gift” legislation implied: “To remain faithful to the popular concept, the proposed legislation must recognize that death is the death of an individual person, not of an organ or cells.”²⁸⁵ This distinction of personhood from embodiment was to be made based on medical knowledge. It is what is known of the process of death (which is what the dominant medical view tells us) that enables distinctions regarding what counts and what does not count to be enshrined in law. Thus, the recommended legislation addresses the application of scientific data in order to establish the point “when an irreversible cessation of all that person’s brain functions has occurred.”²⁸⁶ This *dividing practice* drew the line of which signs counted as enough signs of life to prevent a diagnosis of death at the whole brain. A narrower position would have designated only the cortex and a broader definition included the “residual electrical activities in the brain-stem or spinal cord.”²⁸⁷

Without opposition to death as a matter solely within the medical domain, and the LRC’s assertion that there was a need for new criteria and a universal definition, science was used as the form of knowledge legitimizing the recommended legislation. As such, the Commission took a positivist view that a shift in which signs of life are considered significant enough to constitute the presence of a person is not subjective. This was made clear by repeating a concern expressed by some surgeons at Barnard’s conference that such a law,

...must not create a ‘new death’ but simply provide a new general and accepted method of determining the same reality. Law is there to reflect a change not in the

²⁸⁴ *Ibid.*

²⁸⁵ LRC “Criteria for the Determination of Death” Working Paper 23, 1979 p. 55.

²⁸⁶ LRC “Report on the Criteria for the Determination of Death,” Report 15, 1981. p. 29.

²⁸⁷ *Ibid.* p. 30.

nature of death, but only in the criteria for determining, recognizing and appraising it.²⁸⁸

Yet, this advice fell on deaf ears. Of the options reviewed by the Commission - leave it to the doctor; leave it to the courts; pass legislation - failure to accept and pursue the Commission's recommendation meant that, with the exception of Manitoba, doctors in Canada were left to decide when death occurs.

A decade latter, the Canadian Medical Association added another voice to the LRC in requesting legislation.²⁸⁹ Changing their position on the desirability of legislation, the CMA wanted to ensure medical intervention in live and 'brain dead' patients for another not be considered an offence under Criminal Code provisions to protect bodily integrity. Presenting to a House of Commons Sub-Committee on Justice in 1992, the CMA lobbied to change key provisions to recognize as legitimate the non-therapeutic intervention of body part removal.²⁹⁰ A "old" definition of death in the Criminal Code based on cessation of circulatory and respiratory systems "creates a practical problem for physicians who generally accept that death may be defined in terms of the cessation of brain function."²⁹¹ Thus, the CMA recommended "that death be defined in terms of the irreversible cessation of brain function and/or in terms of the prolonged absence of cardiac and respiratory functions."²⁹² These changes were not pursued.

Just as the key organization of doctors came into agreement with the need for legislation, the Law Reform Commission appeared to accept the medical practice of declaring death based on brain signs as adequate in the absence of enshrinement in law. Working paper number sixty-six produced in 1992 entitled "Procurement and Transfer of Human Tissues and Organs," was prompted by the question of whether the definition of

²⁸⁸ LRC "Criteria for the Determination of Death" Working Paper 23, *op.cit.*

²⁸⁹ Exemption of medical experimentation was also sought. Canadian Medical Association (CMA) "Executive Summary. Brief to the House of Commons Sub-Committee of the Standing Committee on Justice and the Solicitor General on the Recodification on the General Part of the *Canadian Criminal Code*" October 19, 1992.

²⁹⁰ *Ibid.*

²⁹¹ Canadian Medical Association "Executive Summary. Brief to the House of Commons Sub-Committee," 1992. *op.cit.*

²⁹² *Ibid.*

death could be changed again to classify anencephalic newborns as dead.²⁹³ The focus of the paper, however, was on the system of procurement, reflecting a general shift from the question of whether citizens should be used as sources to how this should be done. Aside from addressing the case of anencephalic babies, the only mention of the question of when death occurs is in the introduction where it states that this has been decided:

If a hospitalized patient could continue indefinitely on mechanical support, with no responsiveness and no brain functions, would the patient legally be dead or alive? The answer has become clearer, *because* the proposed brain-death criteria have *become a customary standard* for both modern medicine and law.²⁹⁴

Resolution to this problem is noted to be a good since, “such legal reform reduces uncertainty and confusion. The certainty gives families and medical professionals a contemporary standard for responding to particular life-death scenarios.”²⁹⁵ Remaining steadfastly committed to resolving the ‘cyborg situation’, it is mentioned as a consequence that this change aids a particular *technology of health*:

Transplanting organs from a recently deceased donor involves maintaining the dead body on artificial life support so that the donor’s organs may be preserved until a recipient is ready. The clarity afforded by the new standard for death, then, has also facilitated organ procurement and transplantation.²⁹⁶

Throughout the document, the definition of death referred to is the one the Commission proposed to legislators in 1979 and 1981 recommending the law be amended to define death based on brain function. That legislators ignored this advice and the law in Canada, with the exception of Manitoba, has yet to actively endorsed brain signs as indicators of death is not mentioned.

3.4.1 Death in the United States

In 1981 criterion for death based on brain function became law in the United States following the work of the “U.S. President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.” In keeping with earlier

²⁹³ LRC “Procurement and Transfer of Human Tissues and Organs” Working Paper 66, 199:2.

²⁹⁴ *Ibid.* p. 1. (emphasis added)

²⁹⁵ *Ibid.* p. 2

²⁹⁶ *Ibid.*

attempts to pinpoint the right moment of death, the Commission was guided by the goal of establishing a single set of standards that would allow physicians to “know as early as possible when a mechanically supported patient’s brain ceases to function in order that they could adequately take care of those organs designated for transplant” without being seen as radically changing the meaning of death.²⁹⁷ At the end of their deliberations, the “Uniform Determination of Death Act” recommended by the Commission defined death based on the functioning and relative importance of measurable parts of the brain. Debate in arriving at this conclusion was technical. All participants agreed that the only significant criterion for the deaths they were concerned about was brain function, the debate was over how much brain function.²⁹⁸ Was the cessation of the whole brain necessary or only part of it to declare the life of the person over?

One set of participants viewed the upper cortex as the part that mattered on the grounds that it controlled higher level aspects of life that distinguish human life from other species and made life worth living. Another set argued that brain stem functions regulating autonomic functions also counted as signs of life. With a larger pool of patients to draw on for organs should the amount of brain function necessary to declare death be minimal, the Commission nonetheless chose “whole brain death.” This took a conservative stance while reducing personhood to life status of the brain.²⁹⁹ Two reasons were offered for taking this position: first a tutioristic argument that “because physicians are fallible and frequently make diagnostic errors, it is safer to opt for a whole-brain rather than a neocortical definition of death.”³⁰⁰ Second, they determined that it would not have been socially appropriate to “taking the final step” of burying patients such as Karen Ann Quinlan with some parts of her brain still alive.³⁰¹ She was not dead if judged on the basis of socially acceptable treatment rather than scientific measurement. As a result of the Commission’s recommendations, by 1993 all fifty states and the District of

²⁹⁷ Cecilia M. Schmitz and Richard A. Gray *The Gift of Life: Organ and Tissue Transplantation: An Introduction to Issues and Information Sources* Ann Arbor, Michigan: The Pierian Press, 1993.

²⁹⁸ John Lachs, “The Element of Choice in the Criteria of Death.” *Death: Beyond Whole-Brain Criteria*, Richard M. Zaner (ed.) Boston: Kluwer Academic Publishers, 1988.

²⁹⁹ Margaret Lock “Death in Technological Time,” 1996. *op.cit.* p. 587.

³⁰⁰ The rejoinder to this argument was that it would be safer still to adhere to the traditional cardio-pulmonary standard. But clearly this was something no one was prepared to do. Schmitz and Gray, 1993. *op.cit.* p. 32.

³⁰¹ *Ibid.* p. 30

Columbia had legislatively or judicially adopted of some form of 'brain death' criteria as death.³⁰² According to a text written that year, legislation clarifying life status removed "any indication that this 'alive'/ 'dead' situation remains a possibility in 1993."³⁰³ In Denmark the question of whether 'brain death' was death was considered significant enough for the government to publicize the issue and hold 200 public hearings prior to a decision on its acceptance in July 1990.³⁰⁴ In both these countries and Japan, but not Canada, it was through some form of public deliberation that the *dividing practice* of separating persons from 'non-persons' was decided as the point at which the brain stops functioning.

3.5 Conclusion

Acceptance of 'brain death' 'made visible' a category of 'non-person' from whom organs could legitimately be removed. Allowing surgeons to avoid waiting for the heart to stop to resuscitate it for procurement after a "delay" of a set period of time, changing the definition of death meant that organs could remain perfused. In the West, 'brain death' did not fade away and was not rejected, it moved from a weak and fragile idea to a mere statement to a strong truth. It was not arrived at through a democratic, collective decision that marking the point from person to 'non-person' could occur earlier to allow the utilitarian use of the dying for the living. Rather, medical and legal authorities framed the question of death in terms of scientific methods of verifying reality. Scientific legitimation established an absolute questionable only on the basis of accuracy not ontology, relegating 'brain death' to the world of technical matters rather than social concepts. Diagnostic criterion for 'brain death' illustrate a continual attempt, identified by Margaret Lock, to "to assign the concepts of life and death to scientifically deducible and verifiable categories, and thus to make them indisputable beyond professional medical circles."³⁰⁵

³⁰² *Ibid.*

³⁰³ *Ibid.*

³⁰⁴ Margaret Lock, 1995 "Contesting the Natural in Japan," 1995. *op.cit.* p. 28.

³⁰⁵ Margaret Lock "Death in Technological Time," 1996. *op.cit.* p. 577.

What holds this truth in place, however, is not privileged access to knowledge but the enrolment of physicians, citizens, legal authorities and the Christian religion. Drawing attention to technical means of arriving at diagnostic certainty conceals that the power to determine death emerges not from the superiority of the scientific method but the hegemony and social status of medicine.³⁰⁶ While claiming to “discover” what was already there, the ‘brain dead’ did not exist prior to the creation of this category.³⁰⁷ A type of death did not exist, nor was the absence of personhood consistent with signs of life. Constructing ‘brain death’ “also means the building of a particular associational entity or collectivity that views and acts in accordance with certain ideas and within certain constraints.”³⁰⁸ Widely accepted, ‘brain death’ offers an alternative form of possible society, in which people can serve as natural resources for a particular way of seeking to cure others.³⁰⁹ Thus, by making a point in the process of dying visible and referring to it as a type of death, it became possible to detach the end of personhood from the cessation of the body. This division, separating personal life from biological existence added to the interchangeability of parts as a further step away from the idea of personhood as embodied.

The implications of the category reflect the rationale for its creation in the first place: primarily to access live organs by declaring the person gone.³¹⁰ Ending the obligations accorded to those who are alive prior to the point at which burial would be appropriate enabled body part removal for use by other patients. ‘Brain death’ is thus a category created as an adjustment to reality made to accommodate this *technology of health*. Treating others by transplantation could not proceed unless body parts as objects are available. Thus, the legitimacy of this form of treatment depends on keeping the ‘brain death’ ‘black box’ containing controversies, paradox, dilemmas and ambivalence to the objectification of the body closed. As we shall see in chapter four, ‘brain death’ is strengthened as a concept through routine use in intensive care units of hospitals that began providing ‘donors’ to participate in transplantation.

³⁰⁶ Stephan Fuchs, 1992. *op.cit.* p. 17.

³⁰⁷ Ian Hacking, 1986. *op.cit.*

³⁰⁸ Steven Ward, 1996. *op.cit.* p. 16.

³⁰⁹ Ian Hacking, 1986. *op.cit.*

³¹⁰ Collins, Kendall and Michael, 1998. *op.cit.*

Chapter Four The Discourse of Donation

What we are going through in the postmodern technological scene, is not a 'scientific' revolution but rather an ideological one, a fundamental change in our modes of representation of life. There is clearly a shift in the scale of the techniques involved in contemporary biopower, but not in the scientific logic that sustains them. The real 'break' occurs at the level of the economy of representation that is being deployed to give cultural, legal, moral, and emotional shape to the advent of biopower.³¹¹

Although transplant surgeons developed a way to declare the use of the dying legitimate, this did not address the problem of how to access brain-dying patients in the first place. Attempts in the late 1960s did not supply a sufficient stream of bodies from intensive care units due to "a lack of co-operation."³¹² How this situation changed such that "systems" of procuring parts from bodies became normal and the maximization of which a problematic of the present is the subject of this chapter. Rather than stripping medicine of all metaphorical significance through declaring all brain-dying patients "mere inanimate matter" after a certain point, meaning was attributed to the removal of organs from the 'living dead'. Based on my argument that transplantation requires natural resource bodies in order to produce chimeric bodies, chapter three showed how a process of scientific fact production constructed a category of 'non-persons' from whom it became legitimate to remove organs. The social construction of this legitimating mechanism is the dimension concealed by the second way in which the natural resource body is created: through a moral framework of meaning that serves as a justificatory mechanism to body part removal. I call this the discourse of donation.

The argument made in this chapter is that what granted access to some dying patients for organ removal was not only the legitimation of 'brain death' but also the justification of transplantation as moral as 'organ donation'. This has been accomplished through the construction of a discourse of donation that conceptualizes 'the body' as a gift and presents the 'giving' of body parts as a morally praiseworthy and normal act of individual generosity. The significant effect of this construction is to keep the 'black boxes' of the *technology of health* and 'brain death' closed.

³¹¹ Rosi Braidotti, 1994. *op.cit.* p. 45.

³¹² Stated by Dr. Barnard in reference to the few bodies sent to him following the 1967 heart transplant. Hillel Shapiro, 1969. *op.cit.* p. 274-285.

The removal of body parts is a medical intervention not for the patient whose body is operated upon but for someone else. Maintaining the 'living dead' body, the surgical process of amputation and transferral of parts treats the body in the most utilitarian way - as a mere thing; a means to an ends.³¹³ Yet, the discourse employed to account for this practice uses a narrative of personhood to construct it as for the 'donor', their family and society. Through granting "the body" gift status, personhood is abstracted from embodiment. Ethnologists Renée C. Fox and Judith P. Swazey followed Richard Titmuss in praising the transfer of organs as gift exchange because it embodied the values of universalism they espouse. From a Foucauldian perspective, the emergence of 'the body' as a 'gift' and the creation of a desire to donate enabled access to body parts in a fashion he called 'governing by stimulation'.³¹⁴ This chapter traces the transformations of this discourse from fragile idea to strong truth such that creating natural resource bodies is understood in the West not as an act of mutilation but a "corporeal act of giving" and moral project of nationhood.³¹⁵

What characterizes the discourse of donation is the use of variations of the term donation. To be a donor is to be a 'giver' and therefore moral; to be a 'potential donor' is to possess the opportunity to be moral; and, to participate in the 'donation process' is to contribute to a moral act. This lexicon of transplantation thus establishes classifications that "are constructed to appear to be consistent with cultural 'norms'" of charity and gift giving.³¹⁶ In the same way as 'brain death', 'organ donor' and 'potential donor' are terms that "came into being at the same time as the kind itself was being invented."³¹⁷ By defining all action as moral, this economy of representation ensures questions of human dignity, alive/dead status, personhood and bodily integrity are not provoked in the everyday practices that bring the natural resource body into existence. It also serves to conceal examination of the connection between hospital patients dying in different orders

³¹³ Use of the body as a way of seeking to cure others marks the end point of a trajectory which began with the history of dissection from the 13th century, "which by Descartes's time no longer viewed the corpse as still haunted by the presence of the recently departed soul but as mere inanimate matter like the rest of nature." Gerald P. McKenny, 1997. *op.cit.* p. 188.

³¹⁴ *Ibid.* p. 203-205. McKenny provides an account of this idea as Foucault's concept of biopower.

³¹⁵ Renée C. Fox, "Afterthoughts," 1996. *op.cit.* p. 253.

³¹⁶ Linda F. Hogle "Transforming 'Body Parts' into Therapeutic Tools: A Report from Germany" *Medical Anthropology Quarterly* 10(4): 675-682. p. 680.

³¹⁷ Ian Hacking, 1986. *op.cit.* p. 228.

- the brain-dying as givers and organ-dying as receivers. The bodies necessary to this way of seeking to cure can thereby be produced without problem.

This argument will be made by following the formation of the discourse of donation from 1968 to 1999 as it serves to mobilize allies and resources in alignment with the idea of transplantation as “donation.” By the late 1980s - early 1990s, this discourse attains fact-like status such that supplying organs is asserted to be not only a justified moral activity but an imperative of Western society. Analytical tools from actor-network theory as used within Nikolas Rose’s *strategic* and *assemblage* lines of enquiry to show how discursive practices were used in each decade to establish transplantation as moral as organ donation. *Strategic* identifies the “ways in which medical thought and medical activity have sought to realize themselves.”³¹⁸ This occurred through several processes: the encoding of the body in law as a “gift;” the presentation of a choice “to give;” the formation of a normative commitment towards organ-dying patients; and the construction of a moral imperative to save these patients by supplying organs. From the early 1980s onward, within the context of an alignment of political and medical reason, various allies put forward awareness campaigns, produced donor consent forms and encouraged new grieving rituals using the discourse of donation. A key strategy to inducing participation in transplantation was to insert the presence of the organ-dying patient between brain-dying patient and doctor. As this chapter shall demonstrate, the language of donation and new work practices enable the ‘double medical gaze’, referred to in chapter two, by justifying the positioning of patients as subjects *and* objects of medical intervention - seen as in need of cure and as the source of cure for others - as a matter of moral obligation.

Rose’s category of *assemblages* draws attention to specific spaces of regulation. This chapter will show how the discourse of donation is used to bridge the paradox of *strategic* campaigns which eulogize the donor, and *assemblage* practices that objectify the ‘brain dead’ patient. This is done through linking all hospitals to specifically tasked “organ procurement organizations” (OPOs) and instilling new medical practices in intensive care units (ICU) of hospitals in the name of “donation.” Essential to the production of natural resource bodies in the hospital is the creation and identification of a

new classification of patient: the ‘potential donor’, and ‘donor management’ protocols. Increasingly stringent rules centralizing control over institutional practices based on new categories for transplantation parallel the methods used to access bodies for dissection detailed in chapter two.

The construction of the present knowledge of transplantation is followed as “organ donation” in three parts. The first section examines surgeons’ needs and how law makers responded to the world’s first heart transplant by enacting enabling legislation. Second, around the time of the introduction of cyclosporin, the discourse of donation begins to be publicly articulated through the explicit cultivation of favourable attitudes towards the use of the body to save others. As a result, ‘action at a distance’ is enabled through the funding of medical centres and dissemination of ‘donation’ knowledge in the form of hospital protocols. The third section illustrates how a network of truth formed and is solidified by the declaration of a “shortage crisis” in the early 1990s and claim that generosity is to blame. This led to debates about the procurement “system” built the questionable upon “the unproblematic” ‘black boxes’ of transplantation as a *technology of health* and ‘brain death’, to further contain the truths that hold transplantation in place.³¹⁹ This chronological account ends in 1999 just prior to at the the House of Commons Event at which point in time the transplant episteme is fully formed.

4.1 Experimental Era: 1960-1970s

To conduct transplantation, surgeons needed organs. At Dr. Barnard’s international symposium in 1968, the newly formed cadre of international transplant surgeons closed their meeting with a second mention of the problem of donors. In addition to the matter of what type of patients are suitable, it was recognized that finding and legally accessing such patients was a problem. Two solutions were offered: forming linkages to emergency wards to constantly remind physicians of the needs of other patients and securing legal consent in life for automatic retrieval of organs.³²⁰ As the surgeons saw it,

³¹⁸ Nikolas Rose, 1994. *op.cit.* p. 52.

³¹⁹ Stephan Fuchs, 1992. *op.cit.* p. 222, footnote 2.

³²⁰ Hillel Shapiro, 1969. *op.cit.* p. 254-257, quoted in Margaret Lock “Death in Technological Time,” 1996. *op.cit.*

the natural resource body would arise through knowledge of the benefits to re-using the body, ensuring doctors remember that “material” is needed to treat other patients and by bringing the fields of law, morality and ethics on side. This would ideally take the form of an automatic and unquestioned system of retrieval.

Key to breaking-down the “active resistance” the transplant surgeons encountered against hybridization was to make intensive care unit physicians and citizens “feel this need” that patients dying organ-first relied on them to supply the raw materials needed to save their lives.³²¹ It was this ‘double medical gaze’ to think of their patients as not just subjects but also as objects and sources for patients dying organ-first that transplanters sought to instill to mobilize response. This ‘double gaze’ was concealed by the classification of ‘donor’ which allowed the sight and treatment of patients *for others* to be defined in subjective terms. For example, in 1972 it was remarked that,

Doctors responsible for the care of the fatally injured have a *secondary responsibility* to the community to assist the transplantation programme by selecting and caring for potential organ donors. If they decline this responsibility, they deprive potential recipients of any chance of further useful life by making standard methods of organ transplantation logistically impossible.³²²

‘Potential organ donor’ was the classification - defining a kind of person - created to indicate a patient who could be of value to another in parts. It signalled differential treatment to preserve the quality of their organs prior to and distinct from alive/dead status. An obligation to treat patients as subjects *and* objects was thus formulated through the language of donation, linking the individual to the population on the basis of the claim that both must be served.

Organ-based disease organizations, administrative units and automobile associations came forward as immediate allies, willing to help mobilize support by raising public consciousness of the need for organs and telling the public of the benefit “donating organs” could bring.³²³ With not one recipient living more than a year at this time, it was the possibility not the actuality of cure that served in surgeons’ view to morally justify objectification and the extension of medical intervention beyond death. In

³²¹ *Ibid.*

³²² G.C. Oosthuizen, 1972. *op.cit.* p. 55.

1970 theologian Paul Ramsey wrote that "there is something a little macabre about 7 out of 10 of us or a predictable 80 million Americans becoming a nation of card-carrying precadavers."³²⁴ The contrary view of medical professionals was to view capitalizing on the death of one to save another as rational and humanitarian.

The legal concerns and organizational challenges transplant surgeons faced in obtaining their material came to be alleviated through the public articulation of a social justification for the natural resource body. This occurred as the positive response to Dr. Barnard's world's first heart transplant in 1967. As mentioned in chapters two and three, when Louis Washansky survived the surgery, European and North American media portrayed the surgeon as a hero and declared the event a medical miracle.³²⁵ Echoing this sentiment, Western leaders were quick to embrace what transplant surgeons offered: the hope of cure. In the view of prominent members of the legal profession "no tribute to the courage and humanity of the pioneers can be too high."³²⁶ Their work was not perceived as questionable experimentation on human beings or as mutilating the newly dead to artificially prolong another patient's life against the will of nature. Rather, this group saw transplant surgeons as virtuous in taking extraordinary measures to try to save human life. Physicians were not questioned about saving the life of Denise Darvall. They were trusted completely with respect to her death. This drew upon and reinforced the Cartesian view that her body, and still beating heart, was mere tissue. Holding on to the view of the heart as the seat of the soul, now that medical science provided a "more rational framework," would inhibit scientific progress.³²⁷

Legal experts and politicians acted as allies of surgeons in seeking to protect them from liability by designing a legal and regulatory framework focused on enabling this therapeutic modality. The former argued that jurists "certainly must adapt their rigid, over-conceptualized thinking to the novel conditions" in order to permit this social good.³²⁸ Similarly, the justification offered by State Attorney General Francis B. Burch at a symposium held in 1969 by the Maryland Academy of Sciences, called "Organ

³²³ Hillel Shapiro, 1968. *op.cit.*

³²⁴ Paul Ramsey, 1970. *op.cit.* p. 209.

³²⁵ Margaret Lock "Death in Technological Time," 1996. *op.cit.* p. 581.

³²⁶ David Daube, 1968. *op.cit.* p. 200.

³²⁷ Richard M. Titmuss, 1970. *op.cit.* p. 17. From chapter two, stated by Titmuss with respect to blood.

Transplantation – Current Medical and Medical-Legal Status: The Problems of An Opportunity,” was hopeful enthusiasm for a triumphant opportunity to “save human life.”³²⁹ Utilizing “a peculiarly American theme of a triumphant medical science challenging death,”³³⁰ the Attorney General concluded his speech by stating:

Ladies and gentlemen, we stand on the threshold of a great era in medical achievement. It is for all of us, and particularly the members of the medical profession, to lead the way in the difficult and the arduous tasks which lie ahead. As Pericles shouted to the Athenians when they weakened, ‘You shall not covet the glory unless you endure the toil.’ I am sure that each of you here today is prepared to endure the toil of this great adventure.³³¹

Seen in this light, the noble drive to alleviate suffering and deter - at least one - death served as a value strong enough to justify any adjustments needed to make a source of replacement parts available. To be part of offering citizen’s hope, enabling new developments in medicine was a task of administering life the modern nation-state took up with pride.

This enthusiasm led to the creation of the *Uniform Anatomical Gift Act* which became law in Maryland in 1968. Immediately thereafter, the American Bar Association and numerous medical groups approved and adopted it as their guiding framework.³³² One year later, 25 states had passed the legislation. A Uniform Donor Card for organ and tissue donation was also created by the National Kidney Foundation. With an interest in procurement, organ based disease groups began printing and distributing the card by 1969.³³³ In Canada, a Uniform Law Conference held in 1971 recommended the same type of *Uniform Human Tissue Gift Act* which passed as legislation in all provinces, between 1971 and 1989.³³⁴

The metaphor of the body as a gift one can donate was thereby extended from the legal framework of “gift legislation” designed to allow access to the dead for the purpose of acquiring knowledge through dissection to medical intervention “for therapeutic

³²⁸ David Daube, 1968. *op.cit.*

³²⁹ Honorable Francis B. Burch, 1969. *op.cit.*

³³⁰ Donald Joralemon, 1995. *op.cit.* p. 342.

³³¹ Honorable Francis B. Burch, 1969. *op.cit.* p. 69.

³³² Sadler and Sadler, 1969. *op.cit.*

³³³ *Ibid.*

³³⁴ See chapter three.

purposes.” This ignored the fact that the point at which the body had to be accessed to be valuable to others for therapy (with the exception of corneas) was much earlier.³³⁵ It treated something different - the still ‘alive’ aspect of the body - the same as the dead body. Using terms such as “when the person’s death is imminent,” “upon death,” “at death” and “*post mortem* transplant” as synonyms in the legislation reinforced the donor’s alive/dead status as nonproblematic.³³⁶

As intended, this protected transplant surgeons who could not be accused of causing death by removing organs as long as they declared death of the donor prior to removal of organs or tissues. In practice this entailed recording the time of ‘brain death’ on a death certificate. The determination of death was granted to physicians who possessed the expertise able to determine death. Legislation refrained from listing the criteria of death tests, choosing instead to oblige physicians to act in “in accordance with accepted medical practice.”³³⁷ As the sole legal authority over death, the end of personhood was declared an exclusively medical matter. Consequently, disagreement over its determination became restricted to science as the form of legitimacy exclusive to medical expertise. To avoid the possibility that anything other than science would compromise or influence the definition, *Gift Acts* required that “the fact of death” be determined by at least two physicians without a conflict of interest due to participation in transplant surgery or care of another patient in the hospital in need of an organ.

In making it permissible to give consent to use of a person’s body, gift legislation contributed to a view of “the body” as mere tissue, possessing a property-like relationship to the owner as something that is not “them” but that they own and can alienate.³³⁸ Yet, this utilitarian view was tempered by limiting the degree of alienation of body from

³³⁵ “For scientific research” was also generally added to “for medical knowledge.”

³³⁶ *Human Tissue Gift Act*, Chapter H.20, Revised Statutes of Ontario, 1990.

³³⁷ *Ibid.* Consultants to the U.S. *Uniform Anatomical Gift Act* stated that, “After extensive discussion [considering the wisdom of incorporating criteria into the Act] they concluded that it would not be wise to include a definition of death in the Act, since in the transplant setting, the answer to this question depends largely on medical judgement and since criteria should be flexible to take account of new medical advances as they are made. To freeze a definition into a statute could seriously impede future medical progress.” Sadler and Sadler, 1969. *op.cit.* p. 74.

³³⁸ This is evident in the awkward clause that, “where a gift under this Part cannot for any reason be used for any of the purposes specified in the consent, the subject-matter of the gift and the body to which it belongs shall be dealt with and disposed of as if no consent had been given.” R.S.O. 1980, c. 210, s. 8. (emphasis added)

person by the concept of the “gift.” When attempts were made to initiate organ sales, jurisdictions added prohibitions against commodification. Thus, personhood was fragmented from embodiment in the 1980s through acquiring the quasi-object status of “gift” whereby body parts were declared too much the person to be sold but not too much the person to be given away.³³⁹ Value in human bodies to others used the distinction between monetary and non-monetary forms of economic transfer as a way to contain the potential of maiming or killing persons for their parts. Unlike commodities, gifts could never be fully detached from the giver.

Attributing gift status to the body meant that it ought to be given away but could only be given from the owner. Access to organs was made permissible in North America conditional upon the voluntary consent of the individual in life. Should an individual die “undeclared,” next of kin available at the time may consent on their behalf. As in the century before, persons who die without relatives come under the possession of the state, a representative of which may consent to organ removal.³⁴⁰ More concessionary terms were introduced in Sweden where from 1958 to 1987 consent to removal was presumed unless recorded otherwise.³⁴¹ Revealing that the use of the body was a contentious issue, it was argued in the United States that without a system for registering refusal that could be readily available to surgeons, law suits could arise on the basis of an abridgement of religious freedom or denial of due process.³⁴² To absolve the surgeon of the burden of a lengthy inquiry among next of kin, North American state and provincial statutes selected a express consent model that gave relatives a right of determination by degree of kinship. Nonetheless, the consent of the individual in life was made paramount to the possible objection of next of kin. Redefining the boundaries between individual rights, family

³³⁹ Only replenishable tissues such as blood and sperm can be sold.

³⁴⁰ *Human Tissue Gift Act*, Chapter H.20, Revised Statutes of Ontario, 1990. Section 5.(2) “Where a person who has not given or cannot give a consent under section 4 dies, or in the opinion of a physician is incapable of giving a consent by reason of injury or disease and the person’s death is imminent,” spouse, children, parent, etc. “(f) if none or if none is readily available, the person lawfully in possession of the body other than, where the person died in hospital, the administrative head of the hospital may consent.....to parts of the body being used after death for therapeutic purposes, medical education or scientific research.”

³⁴¹ Nora Machado “The Swedish Transplant Acts: Sociological Considerations on Bodies and Giving” *Social Science and Medicine* 42(2): 159-168, 1996. p. 160.

³⁴² Alfred M. Sadler and Blair L. Sadler, “Medical-Legal Aspects of Transplantation” (speech presented at the Maryland Symposium), Sadler and Sadler, 1969. *op.cit.*

rights and state rights to be exercised by medical professionals, it was only in the absence of written consent or upon knowledge of subsequent withdrawal of consent that a family could veto individual agreement to the removal of body parts.³⁴³ This insinuated an obligation to consult the patient's relatives in case such a situation existed.³⁴⁴ Although legally permissible, whether a physician would wish to proceed if any relative raised objections was considered, "a question of medical ethics and practical public relations."³⁴⁵

Altruism was the model used as a compromise between commodification and state control. As a result, legal provisions enabling citizens to consent to use of the body upon death was not neutral but written in a way that established giving as desirable. It presented being a natural resource for another as a positive opportunity over which the individual had a choice. Key to the formation of this body was therefore not fate or instruction but self-determination. By inscribing meaning upon this activity, these developments established the framework of the discourse of donation, thereafter shaping the practice of transplantation in the West. As a moral framework of right from wrong that ostensibly pitted self-interest (in keeping the gift) against altruism (in giving it away), the body as a "gift" captures Foucault's view that state power increasingly depends on relations and networks through a 'control by stimulation' rather than repression.³⁴⁶ Rather than the Swedish model of automatic appropriation of the 'brain dead', power is productive in this discourse of the body through the central claim that to be used by another, in death and in parts, is desirable.

The explicit cultivation of attitudes and practices favourable to this therapeutic modality utilized the framework of "choice to donate one's gift of life" to enrol the support of the population. Value to others in death and in parts had the effect of granting a place for these considerations in self-constitution and personal identity formation. This placed the choice over whether to declare oneself "a donor" or not as a dimension of self-constitution over which an individual could exercise sovereignty. Most notable in the framework of choice established was that self-determination, and secondarily family

³⁴³ Nora Machado, 1996. *op.cit.* p. 159.

³⁴⁴ If relatives could not be found, as in the case of "street people" such as Mr. Junor of the *R. vs. Kitching* 1976 case in Manitoba (see chapter 3), parallel to the case of vagrants available for dissection (see chapter 2), medical professionals could proceed.

³⁴⁵ Sadler and Sadler, "Medical-Legal Aspects of Transplantation," 1969. *op.cit.*

determination, was granted with respect to disposition of the body “after death” but not over when a person is dead. Insinuated in the ability to “give” away the body was the claim that there was a time of “life” at which one did not need one’s body anymore and could therefore give it away. Detachment of personhood from embodiment was thus implicated in the notion of “the body” as “gift,” and considerations of what constitutes death overshadowed by the focus on choice thereafter.

Using this legal framework, transplantation experiments proceeded throughout the 1970s and early 1980s using the medical criteria for ‘irreversible coma’ and then ‘brain death’ to legitimate certain patients as ‘non-person’ enough to remove their organs. The terminology of “donor” and “recipient” - instead of natural resource and chimera - instilled identities whose relationship was presented as that of two individuals rather than a mixing of the two; with one dependent upon the death of the other for life. Defining organs, like blood, as a “gift” had the effect of making “use of the culturally familiar to legitimize what is in fact a profound transformation in the way we think about and act toward the human body.”³⁴⁷

4.2 1982-1987: Aligning Allies and Building Resources

4.2.1 *Politics and the Medical Miracle in the U.S.A.*

Until the release of cyclosporin in 1984, transplantation surgeries were rare, highly experimental and survival rates so low that this *technology of health* was applied in relative obscurity. What changed this, in addition to the new drug cyclosporin, was the availability of access to brain-dying patients through publicity of a need for organs in the United States. One force behind this development was a convergence in the outlook held by conservative politicians and clinical medicine of society as a collection of individuals. A pattern of public policy formation in the United States that originated with televised campaigns, led to legislative hearings and new hospital regulations which pushed transplantation forward in a pattern that would repeat itself in the 1990s. With the *technology of health* presented as feasible, and the organ-dying brought into view, an

³⁴⁶ Gerald McKenny, 1993. *op.cit.* p. 204 quoting from Foucault, 1980, pp. 56-59

³⁴⁷ Donald Joralemon, 1995. *op.cit.* p. 342.

ethos to do everything possible to deter death also played a part in adding powerful allies to the truth of "organ donation" as moral. By 1987, the discourse of donation solidified into an imperative to supply organs.

Approval of the End-Stage Renal Disease Program in 1972, described in chapter two, established funding for organ procurement agencies (OPOs). These publicly funded units were charged with the task of getting kidneys to supply transplant centres with their material. To aid transplant surgeons, these agents and allied organizations disseminated "organ donor cards" as widely as possible to secure consent prior to hospital admittance. Passed over in asking for consent to donate or not was the question of death. Another measure was an extension of the dreams of surgeons at Dr. Barnard's conference whereby the transplant centre use the OPO to establish a liaison within intensive care units. The Pittsburgh transplant centre was one of the first to create the "procurement coordinator" position, whose job it was to inform transplant centres when a patient dying brain-first became available and approach bereaved families for consent. To successfully compete for funding within the hospital, the centre had to prove itself. The makers of cyclosporin, Sandoz Corporation, could provide funding but not the organs necessary to perform surgery and build success rates. To this end, the kidney transplant program and experimental liver transplant trials on humans, also released positive information to the media for promotional purposes.³⁴⁸ Nonetheless, not enough qualified patients could afford surgery and not enough organs could be found.

To change this situation, transplant surgeon Thomas Starlz approached the U.S. Surgeon General, C. Everett Koop in 1981.³⁴⁹ In spite of his sanctity of life stance, Koop was sympathetic to the need for organs. Starlz saw this as due to the possibility that transplants could cure children with biliary atresia disease, something the doctor had been trying to do for thirty years.³⁵⁰ Taking up transplantation as a preoccupation he would share with other powerful men in the United States, Koop was instrumental to the

³⁴⁸ Thomas E. Starlz, 1992. *op.cit.* p. 269.

³⁴⁹ C. Everett Koop had, according to Starlz, "strong feelings about the sanctity of life (pro-life, anti-abortion)" which made his support from transplantation uncertain. *Ibid.* p. 251. Later a Member of the Reform Party of Canada demonstrates how a claim to be in favour of preserving life at the beginning (against the suffering of a woman) is not held consistent with a stance in favour of preserving the life at the end (against the suffering of an organ-dying stranger).

³⁵⁰ Thomas E. Starlz, 1992. *op.cit.* p. 252.

Consensus Development Review, mentioned in chapter two, that led to the classification of liver transplantation as therapeutic. As well, the Surgeon General standardized the operation to procure organs from the 'living dead'. Requesting a description and drawings of the surgery, Koop disseminated knowledge of organ removal surgery to make 'action at a distance' possible. Students across the country would now learn the cadaveric organ procurement operation as a standard procedure included in medical textbooks.³⁵¹

Augmenting the public relations efforts of organ procurement agencies, the need for an organ became a form of suffering that became a public cause in the early 1980s in the United States. In 1982 the father of a eleven-month-old baby, Jaime Fiske, effectively advertised for an organ by delivering a speech at the national meeting of the American Academy of Pediatrics about his plight.³⁵² CBS Anchor Dan Rather helped ensure all the major television networks covered his appeal. As a result, when a ten-month old baby boy of a Utah family died brain-first in a car crash soon thereafter, they remembered Jaime's need and donated the boy's liver. In another case, the daughter of an army captain named Broderick was denied payment for transplant surgery based on its experimental status under Medicare. As was the case for most patients dying organ-first, both an organ and money to cover the expense of the transplant operation were in need.³⁵³ This family also sought the charity of the American public to supply each of these items. These campaigns represented a challenge to the identity of the nation as generous and able to provide for its people. In Pittsburgh, transplant surgeon Thomas Starlz recounts in his memoirs how,

...the inability of people who needed these organs to find or afford them was a cause for outrage. Symbolic was the nightly pleading on television by the parents of desperate yellow-skinned children with liver disease, abandoned by the health care system because of lack of money or the alleged absence of a cadaver organ procurement system.³⁵⁴

³⁵¹ *Ibid.* p. 259, 271. The pictures appeared in T.E. Starlz, T.R. Hakala, B.W. Shaw, Jr., R.L. Hardesty, T.J. Rosenthal, B.P. Griffith, S. Iwatsuki, and H.T. Bahnson, "A Flexible procedure for Multiple Cadaveric Organ Procurement," *Surgery, Gynecology, and Obstetrics* 158:223-30, 1984.

³⁵² Keith J. Mueller "The National Organ Transplant Act of 1984: Congressional Response to Changing Biotechnology" *Policy Studies Review* 8(2): 346-356, 1989. p. 347.

³⁵³ *Ibid.*

³⁵⁴ Thomas Starlz, 1992. *op.cit.* p. 269. In 1987 the U.S. government passed a law which requires that

This publicity introduced to the public the idea of giving an organ. It also conveyed the messages that: transplantation was now a feasible means available and capable of saving lives; that the demise and use of patients dying brain-first was not a concern and that the giving of an organ was equal to the giving of money. In addition to the novelty of the story, the plight of the organ-dying was presented as unjust. Denying access to the means to save a life when such means existed due to a lack of private resources struck a chord with the vast majority who did not have health care insurance. The mobilization in support of "donation" that resulted parallels Nikolas Rose's observation with respect to the hygiene movement that "the struggle against a disease had to begin with a war on bad government."³⁵⁵

A rise in the number of transplant surgeries performed, from 103 in 1982 to 346 in 1983, and longer survival rates once cyclosporin received FDA approval in 1983, gave rise to a surge in demand.³⁵⁶ Patients and families began to have more faith in finding a cure through replacement and were driven by the noble quest to save life by any means necessary.³⁵⁷ Although a year earlier organ-dying patients would have been considered "terminally" ill now they were considered to have "end-stage" organ disease. This cast the problem in terms that repeated the basis upon which public policy on kidney dialysis and transplantation formed: lack of treatment could not be considered ethical when presented within "a strong rhetorical framework" of a "simple dichotomy of life versus death" for these patients.³⁵⁸ If a means was available to relieve this form of suffering, failure to provide it meant organ-first deaths were a fault of society, not nature. Lack of access to this therapeutic modality thus became a rallying call against what was seen as an immoral and unjust private health care system. Through these connections, blame for each needed resource - the organ and money - was directed at the system rather than provoking questions about how dead brain-dying patients need to be, how "donors" died, according to what definition of death and in what numbers. The problem was thereby

transplant centres disregard patients' publicity campaigns, the wishes of donors, a patient's ability to pay and other such factors in organ allocation. Schmitz and Gray, 1993. *op.cit.* p. 17.

³⁵⁵ Nikolas Rose, 1994, *op.cit.* p. 56.

³⁵⁶ Donald Joralemon, 1995. *op.cit.* p. 335.

³⁵⁷ Gilbert Meileander, "Second Thoughts About Body Parts" *First Things: A Monthly Journal of Religion* 62: 32-37, 1996. p. 37.

formulated with one patient in mind, not two, building on an assumption that this technology had no inherent limits.

President Ronald Reagan personally responded to cries for help getting organs by making direct appeals for assistance to individual cases.³⁵⁹ Liver transplant surgeon Starlz recalls how this powerful ally helped construct transplantation as moral.

He talked of it often on his weekly Saturday morning radio broadcast and offered air force planes to children who otherwise were unable to find emergency transportation to Pittsburgh in time to receive their new livers...[his] personal attention to the problem had a greater positive impact on organ donation than any other single factor in the mid 1980s. Before July 1983, the supply of donors was a trickle. During the next twelve months, this changed to a torrent, and fifty-one infants and children were treated at Children's Hospital in Pittsburgh. The liver recipients became known as the 'Reagan children,' to the delight of Reagan's supporters and the chagrin of his detractors, who accused him of hypocrisy.³⁶⁰

Other politicians, such as Richard Lamm, governor of Colorado from 1978 to 1986, saw transplantation as the epitomy of fiscal irresponsibility and irresponsibility in health care. He argued with Starlz publicly that "a compassionate society should first give everyone basic health care – then, as resources allow – move to more complicated procedures."³⁶¹ Saving specific individuals was in Lamm's view contrary to the duty to use limited resources to save the maximum number of citizens. Starlz's position in response was that,

When the state is seen as the agent and protector of the good of the public, notions of the state can always be placed ahead of the needs or claims of the very individuals whom the state supposedly serves...an individual life is above bartering...the taking or debasing of life by withholding effective treatment ought not to be justifiable no matter how great the offsetting 'benefit' to the public good.³⁶²

His position, guided by "an ethical standard informed by the doctor-patient relationship," was an individualistic view of society that matched the individualism of conservative

³⁵⁸ Alonzo L. Plough, 1986. *op.cit.* p. 117.

³⁵⁹ Thomas E. Starlz, 1992. *op.cit.* p. 272.

³⁶⁰ *Ibid.*

³⁶¹ *Ibid.* p. 281.

³⁶² *Ibid.* p. 286.

politicians such as President Reagan.³⁶³ For both men, those who could not afford health care did not come into view. While medicine had come to play a powerful role in managing the population, it was curative medicine that prevailed. Political action, in the name of health, responded with high-technology solutions to fix the ill who made it on to nightly television. It was customary for President Reagan to use dramatic narratives – accompanied by photo opportunities or in a “fireside chat” television show – to glorify the stories of average Americans while identifying himself with the cause of the needy.³⁶⁴ The alliance in vision between neo-liberalism and medicine contributed to the conditions for the emergence of “organ donation” as a problem of American society. The organ-dying as innocent victims of biology appeared to position them as the new “deserving poor.”

Responding to public criticism, Democrat and Republican politicians also took up the cause of organ supply at the legislative and executive branches of government. Where body parts were the primary object of transfer, politicians of right and left ideologies agreed with helping the needy. Both supported this *technology of health* through the metaphor of “organ donation” as giving “the gift of life.” Republicans like Reagan carried a tradition of philanthropy based on a charity model of paternalistic benevolence restricted to individuals truly in need and deserving of sympathy. For socialists, gift giving is seen as a superior model of social relations that stands in opposition to the commodification and alienation of the marketplace. Giving body parts from the ‘living dead’ did not fit the model of gift economies – since it could not be reciprocated – but this was overlooked.³⁶⁵ Supporters of the welfare state valued the communal and insurance attributes of gift giving blood and organs for “building a diffuse solidarity of strangers” akin to monetary transfers.³⁶⁶ Without making a distinction

³⁶³ *Ibid.* Starlz’s question “who decides who is to be rescued and who is to be left behind?” with respect to the use of tertiary medical care, extended to apply as a question to all kinds of care is the question that did not find a place in public or political debate. As his book testifies, the care that “often enables the patient to evade death or prevents permanent invalidism in what may seem to be heroic rescue” prevailed. P. 287.

³⁶⁴ Kathleen Hall Jamieson, *Eloquence in an Electronic Age: The Transformation of Political Speechmaking* New York: Oxford University Press, 1988. p. 141.

³⁶⁵ Grieving rituals developed in the 1990s whereby donation provides meaning to the “donor family” could be argued to be what is received in exchange for giving “the gift of life.”

³⁶⁶ In 1970 Richard M. Titmuss wrote *The Gift Relationship: From Human Blood to Social Policy*, *op.cit.* conceptualizing blood transfusion as the modern, rational expression of nation-based solidarity. See chapter 3, page 36, footnote 97.

between parts of the body, both transfers of the body and of money were forms of universal social security this group conceptualized as a right and responsibility of citizenship. Along these lines, some Americans saw in transplantation the opportunity to make universal access to basic health care a reality, by moving the commitment to fund the most expensive treatment to a willingness to fund the least.³⁶⁷ “Donation” of organs was thus seen as progressive and widely supported because body parts were a natural resource the re-distribution of which appeared to come at no cost. Even if a politician had reservations, she/he could not be seen to be against altruism, or science, technology and medicine as rational and humane means to social progress in a secular society. A combination of these forces led entrepreneurial Congressman Al Gore to introduce legislation aimed at making more organs available to families in need. The Congressional hearings on “the Gore bill” that followed forshadow much of what occurred in Canada at the House of Commons Event in 1999.

Five days of hearings held by the Subcommittee on Investigations and Oversight “was a means of both publicizing the problem and developing legislative solutions.”³⁶⁸ Witnesses testifying about their problems obtaining an organ and financing the operation included the Fiskes, Captain Broderick with his daughter and other transplant recipients.³⁶⁹ Personal stories were put into a framework for action by medical and other experts who defined the issues for legislators and the public. As a resource to provide evidence to support transplantation, survival statistics were presented as proof that liver transplants were therapeutic rather than experimental. Following this debate, the focus turned to ways to ameliorate the main problem: low supply of organs. Suggestions by witnesses included: presuming consent to use cadaver organs unless objection is

³⁶⁷ George J. Annas “The Paradoxes of Organ Transplantation” *American Journal of Public Health* 78(6): 621-622, 1988. Annas points out that Massachusetts became the first state to seriously consider universal health care for its citizens four years after adopting a ‘transplantation for all’ policy. However, as noted in chapter two, medical insurance to cover renal disease contributed to Medicaid coverage of other transplants but not other catastrophic diseases. Alonzo L. Plough found that by 1986 renal disease was still the only illness that qualified for full treatment cost coverage for almost all patients under Medicaid. The hope of leading to an extension of medical insurance coverage has therefore yet to materialize. Plough, 1986. *op.cit.* p. 119.

³⁶⁸ Keith J. Mueller, 1989. *op.cit.* p. 348.

³⁶⁹ *Ibid.*

recorded; encouraging state adoption of brain-death statutes and massive public education.³⁷⁰

Legislation that followed this event aimed to improve “the organ procurement system” by educating the public of their choice to donate and ensuring medical staff cooperation. The *National Organ Transplant Act* of 1984 contained five major provisions: federal grants to existing and new organ procurement agencies, a national network for organ distribution, cost coverage for expensive drugs such as cyclosporin, a task force and the prohibition of the purchase of organs.³⁷¹ The latter was a specific response to the outrage provoked by a Virginia physician’s proposal to broker kidney sales between the organ-dying and Third world or impoverished American living donors.³⁷² This attempt and the reaction to making the natural resource body through purchase and sales parallels the formation of a black market in cadavers sold for dissection in the nineteenth century, as described in chapter two. Taken as a marker of the extreme that had to be avoided, the threat of commodification had the effect of strengthening the argument for regulation. It did not provoke questions about this way of seeking to cure, the implications of human beings possessing value to others in death and in parts or the potential implications of demand driven by a quest for immortality.³⁷³ The systemic concealment of the first death emerged through what was unique about the public campaigns and legislative hearings: speaking of body parts without mention of persons. Personhood thus moved further away from embodiment through the objectification of the body, in parts, as “gifts.”

4.2.2 *Mobilizing Medicine through the Discourse of Donation*

With funding and a mandate, four sites of professional activity were enacted to move the discourse of donation into practice. Early surgeon’s vision of a “system” of automatic retrieval to facilitate transplantation began to be implemented as each ally established governmental systems to grant greater access to the ‘living dead’. Organ procurement organizations became permanent agencies, hospitals were issued guidelines

³⁷⁰ *Ibid.*

³⁷¹ *Public Law 98-507* in Schmitz and Gray, 1993. *op.cit.* p. 9.

³⁷² Keith J. Mueller, 1989. *op.cit.*

³⁷³ See Nancy Scheper-Hughes “The New Cannibalism,” 1998. *op.cit.*

for “donation services,” legislation tightened *Gift Acts* to improve consent rates and medical professionals claimed “organ donation” as a moral obligation. Given that “the body” as a “gift” implied the desire to donate, it was not generosity but negligence on behalf of the medical profession that came to be blamed for insufficient organ supply in the late 1980s.

Organ procurement organizations were established as the lynchpin in the “procurement system.” As permanent administrative apparatuses, OPOs grew out of co-operation agreements between transplant centres in large cities. A Vancouver based organization grew into the BC Transplant Society in 1985. Similarly, a Toronto area network linking intensive care units to transplant centres expanded in 1988 to Ontario’s Multiple Organ Retrieval and Exchange Program (M.O.R.E.) to cover the whole province. The city-wide networks were formed to address two problems: competing for access to patients dying brain-first in intensive care units, and public concern that organ distribution was skewed by competition between centres or influenced by connections.³⁷⁴ Establishing a liaison unit between intensive care units and transplant centres reinforced rules governing distribution while strengthening the procurement system. As autonomous agencies, OPOs gave surgeons and the organ-dying dedicated representatives assigned the exclusive task of obtaining organs on their behalf. A task force recommended at the time that M.O.R.E. be established “to find a way to share organs quickly and fairly and to help increase awareness about organ donation and transplants.”³⁷⁵

To address the distribution issues, OPOs took over waiting lists of organ-dying patients waiting for an organ kept by transplant centres and computerized algorithms city-wide networks had designed to give credibility to organ distribution. A central waiting list was established based on OPO jurisdiction ranking patients according to objective criteria of need.³⁷⁶ Following clearly laid out rules, the first biologically compatible patient on the list would be the first candidate for transplant surgery when the right organ became available. This system served to assure the public that every donor has an equal

³⁷⁴ Dr. Calvin Stiller “Overview of Transplantation in Canada” in Health Canada “Report of the National Consensus Conference on Safety of Organs and Tissues for Transplantation,” October 29-31, 1995.

³⁷⁵ <http://www.transplant-ontario.org/aboutf.html>

³⁷⁶ J.E. Murray, 1992. *op.cit.*

chance at being a recipient. Public trust in fair distribution was a goal of transplant centres aimed to ensure concerns over who would receive an organ did not stand in the way of the choice to donate.

To increase the organ supply, OPOs utilize scientific legitimation of ‘brain death’ as truth and the discourse of donation of transplantation as moral as “donation” to address two audiences: the mass public in awareness campaigns and medical professionals working in hospitals. In conjunction with regional transplant centres, OPOs provide materials for speaking engagements, mall displays or media contacts for ongoing promotion of “organ donation.”³⁷⁷ In their *assemblage* role in hospitals, OPOs extended their ability to find organs by establishing, from the mid-1980s onward, a network of “procurement coordinators” who connect intensive care units to OPOs. When a patient dying brain-first arrives, the status of ‘potential donor’ declares them a legitimate object of medical attention for another, justifying differential treatment initiated by the “co-ordinator.” To provide evidence for their work, OPOs also engage in “creating, maintaining and monitoring a framework of standards, policies and procedures, collecting and disseminating statistics, and, advocating for appropriate resources and mechanisms to optimize organ donation.”³⁷⁸ From the mid-1980s to 1999, OPOs have become increasingly large-scale and complex systems of organ acquisition.³⁷⁹ A critical resource to the possibility of transplantation, creating natural resource bodies in order to produce chimeric bodies became the designated task of nine OPOs in Canada and numerous OPOs through the United States and Western Europe.

A second public policy change was to instill new medical practices within the site of the hospital. In Canada, the federal government’s Department of Health and Welfare released guidelines for *Vital Organ Transplant Centres* and *Organ and Tissue Donation Services in Hospitals* in 1986.³⁸⁰ To access organs, the *Donation Services* document uses

³⁷⁷ <http://www.transplant-ontario.org/missionf.html>

³⁷⁸ *Ibid.*

³⁷⁹ Nora Machado cites Berward Joerges’ work which analyzes organ transplantation systems as “large-scale technical systems with networked operations that are technical and non-technical in character.” Machado, 1998, *op.cit.* p. 7.

³⁸⁰ Canada, “Vital Organ Transplant Centres” and “Guidelines on Organ and Tissue Donation Services in Hospitals” (*Donation Services*) Report of the Sub-Committee on Institutional Programs, Guidelines for Establishing Standards for Special Services in Hospitals. Ottawa: Department of Health and Welfare Canada, Health Services Directorate, Health Services and Promotion Branch 1986.

the discourse of donation to mobilize hospital staff to participate and become active agents in encouraging families of 'potential donors' to chose to donate. The *Donation Services* document first and foremost informs readers of the legitimating and justificatory reasons for participating in this *technology of health*.

Unlike other high technology problems in which treatment can be booked on an elective basis, the majority of transplant candidates must wait for a commodity in short and uncertain supply and of unknown and unreliable quality. Changes in neurosurgical procedures, legislative changes (e.g. seat belt legislation and legislation related to protective helmets) and other factors may further affect donor availability. In the meantime the quality of their lives may deteriorate and in the case of cardiac and liver recipients life may end before a suitable donor organ is found.³⁸¹

Transplantation is legitimate on the ground that what is utilized – an organ – is just a thing. What justifies obtaining this “commodity” is a normative commitment to the organ-dying with no mention of the ontological status of the ‘donor’ or ‘donor organs’. Transplantation is described not on the basis of the way this therapeutical modality works but by what it accomplishes: an “opportunity for an improved quality of life or for a second chance at life.”³⁸²

Repeating the message of responsibility to exercise a ‘double gaze’, staff are told that “organ transplantation depends on the altruistic nature of people to help their fellow humans.”³⁸³ More directly, the reason to participate is that “donation provides the donor family with a means to assist others and also to alleviate its grief in the loss of a loved one.”³⁸⁴ This message implies that the institution of the hospital now has the opportunity and therefore the responsibility to provide a medical means to alleviate grief. The domain of medicine is thus extended into the space formerly held by religion. Added to the task of curing the ill is the task of providing meaning for life through death.

³⁸¹ *Ibid.* “*Donation Services*” p. 7, 8.

³⁸² *Ibid.* p. 1.

³⁸³ *Ibid.*

³⁸⁴ Canada, *Donation Services*, 1986. *op.cit.* p. 3. Stating that donation is an opportunity to do good, a section on religious considerations does note that Jewish, Roman Catholic and Protestant faiths do recognize “the moral and ethical justification, medical need and legal basis for organ and tissue donation and transplantation,” but notes that Jehovah Witnesses do not have an official position. “Hospitals must decide whether or not these families should be offered the opportunity to donate.” p. 17.

To service the organ-dying, the *Donation Services* guideline calls for the integration of “organ donation systems.” Medical professionals and hospitals are instructed to identify a new category of patients called ‘potential donors’. This term manages “the ambiguity that comes from their indeterminate status between ‘persons’ and ‘things’.”³⁸⁵ To determine their level of involvement, hospitals should review past deaths to estimate the number, type and seasonal presence of ‘potential donors’. These statistics are to be used as a baseline for future periodic audits and evaluations of the service.³⁸⁶ Recognizing young victims of a head injury, patients with a brain tumor or stroke, hypoxia of the brain, drug intoxication, metabolic disorders, homicide and suicide as ‘potential donors’ triggers a “donation process” in place of the dying process. Affirming that other patients have a sanctioned interest these patients for their organs, the guideline states that the decision to resuscitate is to be made with the possibility of donation in mind in addition to the judgement of whether they will survive.³⁸⁷ A “hospital organ donation officer” is also notified in order to contact the nation-wide network of “transplant coordinators” situated in OPOs or regional transplant centres. Embracing the view of donation as desirable, the family is first informed of the *prognosis for ‘potential donor’* and introduced to the concept of donation. Brain death is then diagnosed, donor support begins and the family is approached by the officer for a decision about donation.³⁸⁸

Although ‘potential donors’ are classified as sources prior to death, it is made clear that no surgery should occur until after “the diagnosis of brain death, the pronouncement of death [and] signed endorsement/consent of the family” is recorded on the patient’s chart.³⁸⁹ The *Donation Services* guideline notes that “the time of death will

³⁸⁵ Linda F. Hogle, 1996. *op.cit.* p. 680.

³⁸⁶ Canada, *Donation Services*, 1986. *op.cit.* p. 11, 53.

³⁸⁷ *Ibid.* p. 29, 8 The “apparent futility of aggressive treatment” for the patient’s survival is no longer a reason not to resuscitate. Similarly treating the patient as a potential donor while still alive, liver transplant surgeon Thomas Starlz saw the shift to resuscitation for all as an improvement on the previous practice of emergency room physicians making the efforts only if the patient was estimated to survive. “With the wide acceptance of brain death in the Western world, all injured patients who come to the hospital in a helpless condition could have a fair trial at resuscitation. Then, in an orderly way, it can be determined whether these people already were dead but with functioning hearts and lungs, or if they had a chance of restoration of brain function.” Resuscitating all patients who arrived in intensive care gave both patients a chance at survival. Thomas Starlz, 1992. *op.cit.* p. 148.

³⁸⁸ *Ibid.* p. 6-7 (emphasis added) It is noted that the sequence of events may vary.

³⁸⁹ *Ibid.* p. 38.

be recorded as the time of brain death documented by the first physician” on the medical record and death certificate.³⁹⁰ Criteria for the diagnosis of ‘brain death’ included in the annex notes that the Canadian Congress of Neurology in 1986 developed these criteria “particularly to avoid diagnostic complications and the possible deterioration of body organs during tests for apna.”³⁹¹ Staff are thus instructed to follow the rules and use caution but be aware that “to delay the declaration of brain death risks loss of a potential donor from intervening cardiac arrest or the deterioration of organs initially suitable for transplantation.”³⁹² By establishing ‘brain death’ as a mere step in the “donation process,” the initial statement is now integrated into routine practice, a matter “about which they need to know nothing but its input and output.”³⁹³ This discussion of ‘brain death’ as a matter possessing the status of “stable, reliable and without risk” affirms its containment in a ‘black box’.³⁹⁴

Other instructions to ensure medical practice for transplantation is realized is the recommendation of a “dynamic and multifacted” in-service and public education program. Continuing education for staff should include: “basic information of the state-of-the-art” technology, including benefits for donor families and transplant recipients and the “professional responsibility to participate in the donation process and related ethical and legal issues.”³⁹⁵ To further provide meaning for staff,

An important ingredient in education programs is feedback to staff involved in donations. Where possible, opportunities for staff of donor hospitals to meet or communicate in writing with transplant recipients should be provided.³⁹⁶

Knowledge of gratitude confirms donation services as a worthwhile endeavour. The reason for public education and community liaison is to facilitate organ acquisition, since, “families unfamiliar with the concept of donation are less able to deal with it when a

³⁹⁰ *Ibid.* p. 31.

³⁹¹ *Ibid.*

³⁹² *Ibid.* p. 30.

³⁹³ Bruno Latour, 1987 *op.cit.* p. 2-3.

³⁹⁴ *Ibid.* p. 29.

³⁹⁵ Canada, *Donation Services*, 1986. *op.cit.* p. 14.

³⁹⁶ *Ibid.* p. 16.

loved one dies.”³⁹⁷ To this end, donor cards and brochures may be displayed in the hospital lobby.

Another rationale made in the *Donation Services* guideline to mobilize participation in the “donation process” was formulated on the basis of a claim which implied that there were enough people dying, just not enough giving. This came about through the production of evidence to support the idea, alluded to in 1972, that medical professionals were responsible for the insufficient supply of organs. To demonstrate that organs could be found, the guideline cites two statistical studies dated 1985 and 1986. This research concluded that: “only about 12% of potential cadaveric organ donors become actual donors. If only 50% of them were to become donors there could be more than sufficient organs.”³⁹⁸ Satisfying demand for organs, based on projections of future need was another reason given for participating in providing sources for transplantation:

As the criteria for donor selection widen and preservation techniques improve, the potential number of usable organs and tissues will increase. However, expanded criteria for recipient selection, increased recognition of transplantation as an accepted treatment modality and more indications for transplantation will result in the earlier referral of more patients. The chronic shortfall of organs and tissues for transplantation could intensify.³⁹⁹

A limit in the number of patients who can receive treatment by replacement based on the number of patients who can donate is not raised as a possibility. By building sympathy for organ-dying patients, “hundreds of whom are on waiting lists,” into the *Donation Services* document and forming a language based on derivatives of “donation,” any mention of death in relation to the natural resource/donor is rendered invisible.

At the same time in the United States, transplant centres and OPOs began to find that in spite of the 1984 *National Organ Transplant Act*, the new measures failed to generate “a sufficient supply of organs to meet the current demand for them.”⁴⁰⁰ Taking legislative action, an *Omnibus Budget Reconciliation Act* of 1986 passed a regulation

³⁹⁷ *Ibid.* p. 15.

³⁹⁸ *Ibid.* p. 1 The titles of the two studies are notable: Stiller, Clavin and Neil McKenzie. “A Plea For the Heart, The Kidney, The Liver, The...” *Medical Post*, February 5, 1985 and Gilmore, Ann, “Producing Donor Organs : Firm but friendly encouragement required,” *Canadian Medical Association Journal*, Vol. 134, April 15, 1986. P. 932.

³⁹⁹ *Ibid.* p. 3.

⁴⁰⁰ Schmitz and Gray, 1993. *op.cit.* p. 10.

establishing hospital participation in Medicare and Medicaid programs conditional upon having in place written protocols to identify 'potential organ donors' and notify organ procurement organizations. Government funding thus became contingent upon compliance with national population management objectives.⁴⁰¹ Organ procurement organizations also identified the *Uniform Anatomical Gift Act* of 1968 as a barrier. Following the recommendations in a report by a prominent bioethics institute, the Hastings Centre, a revised *Gift Act* was passed in 1987 strengthening rules governing access to organs. First, the Revised *Gift Act* reinforces that consent of next of kin is not required when individual consent in the form of a signed "document of gift" is present. Second, all emergency personnel, police, firefighters and paramedics, are assigned the duty to search for a "document of gift" on victims at accident sites.⁴⁰² Third, hospitals must follow a "required request" policy of asking "Are you an organ donor?" to each patient over 18 years of age upon admittance. If the patient answers "no" or does not reply, the admitting officer must discuss the option to donate with the patient and enter the response on the patient's medical records. Such protocols illustrate some of the "varied and complex ways in which practices of truth situate persons in particular relations of force."⁴⁰³

Adding to the momentum in favour of resolving the organ shortage problem by increasing donation, the Canadian Medical Association (CMA) added its voice as an ally of transplantation via the discourse of donation. For this organization, the problem to address to rectify the system is not consent but the negligence of the medical profession to ask for it. Recognized in a policy statement on organ donation issued in 1987 is that fewer than three percent of all deaths "provide suitable organs for donation."⁴⁰⁴ Nonetheless, the problem and its solution is defined in the same way as in the *Donation Services* document: that the key to resolving the shortage lies in identifying 'potential donors'. Also repeated is the presentation of this *technology of health* as unproblematic, which means that the demand for organs must simply be met.

⁴⁰¹ Nikolas Rose, 1994. *op.cit.*

⁴⁰² Schmitz and Gray, 1993. *op.cit.* p. 13.

⁴⁰³ Nikolas Rose, *op.cit.* p. 53.

⁴⁰⁴ Canadian Medical Association "Organ donation" Policy Summary *CMAJ* 136: 752A, 1987. (This policy was under review as of May 1998.)

Organ transplantation is now a recognized form of treatment. No shortage of potential organ donors exists, and public opinion toward organ donation is generally favourable. The demand, however, for donor organs has outstripped the supply. A major barrier to organ donation has been the incomplete commitment of the medical profession to identify 'potential donors' and seek consent from the nearest relatives.⁴⁰⁵

Evidence to support the claim that there would be sufficient organs for all potential recipients, if physicians co-operated, refers to the exact same percentages the guideline on *Donation Services* document cited. On these grounds, the association announced support for "the concept of 'recorded consideration'" which requires hospital staff to routinely "consider the suitability of a dying or 'brain-dead' patient for organ donation in time for donation to occur."⁴⁰⁶ "To increase physicians' awareness of their role in initiating organ donation," every death that fits "established donor criteria" should be followed by consideration for donation, the outcome of which is documented in the medical record by the attending physician.⁴⁰⁷ It is clearly stated that this is not done for organ-dying patients who need replacements but for brain-dying patients:

The application of recorded consideration is viewed as a service for the deceased and his or her family by providing the option to donate...When adopted as hospital policy the emphasis is on the positive aspects of organ donation as an important and recordable event.⁴⁰⁸

As hospital policy, "recorded consideration" does "help the medical profession fulfil its professional duty of obtaining life for others following the brain death of a patient."⁴⁰⁹ Promoting the aim "to maximize the number of donors identified" as a moral obligation, the CMA endorsed the work of the federal government establishing guidelines for institutions to this end. The province of Ontario moved ahead on this goal in 1990 by

⁴⁰⁵ *Ibid.*

⁴⁰⁶ *Ibid.*

⁴⁰⁷ Note that this consideration by the attending physician (along with different forms of intervention to protect the organs) undermines the spirit of the "decoupling rule" separating physicians who attend the donor (specifically to declare death) from those who attend the potential recipient and participate in transplant surgery.

⁴⁰⁸ CMA "Organ donation" Policy Summary, 1987. *op.cit.*

⁴⁰⁹ *Ibid.* A second effort to contribute was a organ donor recruiting campaign to present all physicians in Canada and their families the opportunity to sign an organ donor consent card.

changing *The Public Hospitals Act* to add a requirement that hospitals have policies and procedures to be in place to identify 'potential donors' and approach their families.⁴¹⁰

By 1990 Canada had 28 transplant hospitals, 86 dialysis facilities, 8 organ procurement organizations and a Canadian Organ Replacement Register (CORR). The number of transplants performed in Canada more than doubled from 484 in 1981 to 1189 by 1989.⁴¹¹ Endorsement by more powerful and authoritative actors strengthened the discourse of donation establishing transplantation as moral as "organ donation." Measures taken to change medical practice and regulate hospitals to produce organs parallel the nineteenth century efforts to access cadavers discussed in chapter two. Changes within *assemblage* sites moved the truth that this way of seeking to cure is justified as the moral act of "organ donation" through the "mundane, material practices of looking, seeing, experimenting, calculating, measuring, and writing" the natural resource body into existence.⁴¹²

4.3 1988-1999: The "Supply Crisis"

In spite of the establishment of a "system" to routinize the procurement of organs, an adequate supply of organs capable of meeting demand has remained elusive. Rather than prompt a questioning of transplantation as a *technology of health* or raising questions about donors, the response to the problem of organ shortage from 1988 to 1999 was consistently framed as a matter of trying harder. Within the discourse of donation, in which the giving of organs is constructed as desirable, the problem of insufficient supply could only be understood as a problem of generosity. Retaining the view that people would give if asked, insufficient supply was attributed to ignorance of the ability to give or negligence in the asking and procuring.⁴¹³ To address these two problems, governmental techniques of *strategic* campaigns, legislation and *assemblage* regulation

⁴¹⁰ Resolution 518 of *The Public Hospitals Act*, Multiple Organ Retrieval and Exchange Program of Ontario (M.O.R.E.) website (<http://www.transplant-ontario.org/aboutf.html>)

⁴¹¹ Law Reform Commission of Canada "Procurement and Transfer of Human Tissues and Organs" Working Paper 66, 1992. p. 9 Taken from Canadian Organ Replacement Register (CORR), 1988 Report and 1989 Report, Canada: Department of Health and Welfare.

⁴¹² Nikolas Rose, 1994. *op.cit.* p. 62.

⁴¹³ Gilbert Meilaender, 1996. *op.cit.*

applied in the 1984-1987 period were repeated and intensified. By the mid-1990s, the continued failure of the "procurement system" to produce enough organs led to debate regarding the adequacy of the express consent model as established in *Gift Acts*.

To view the "organ supply" relative to the number of organ-needy patients waiting for a replacement, national databases were created such as the Canadian Organ Replacement Register.⁴¹⁴ In 1990, statistics on liver, pancreas, heart and lung transplants were incorporated into a pre-existing renal and dialysis database that was established in 1981. Also added was the number of patients on waiting lists and, in 1992, information on donors. This allowed an "organ donor rate" to be published on an annual basis for each jurisdiction. Embedding the discourse of donation into the practice of counting and presenting "factual" information, the rate was measured as the percentage of donors per million population rather than as a percentage of 'potential donors' or 'brain dead' patients. This presented all citizens as able to donate, effacing the qualifying factor of dying first and dying brain-first. In measuring how many patients "remained waiting," meeting the needs of the organ-needy shifted from surviving transplant surgery and living long thereafter to the expeditious provision of organs. Donor numbers, and the supply and demand language of economics, rather than the significance of giving the gift,⁴¹⁵ thereby assumed a salience as a comparative index of the nation based on the utility of its citizenry.

Centrally collected quantitative evidence confirmed that the number of transplant surgeries rose throughout the 1980s as did the number of patients who qualified for a replacement. However, as demand increased, the steadily climbing organ supply began to stagnate in the United States in 1986 and later in the mid-1990s in Canada.⁴¹⁶ On occasion an article or transplant centre webpage would mention decreasing traffic fatalities, better health care, or new surgical techniques saving people who may have

⁴¹⁴ CORR is funded by the federal and provincial governments, the Canadian Society of Nephrology, Canadian Transplant Society and Canadian Association of Transplantation.

⁴¹⁵ Fox and Swazey, 1992. *op.cit.*

⁴¹⁶ See U.S. reference Prottas, Jeffrey *The Most Useful Gift: Altruism and the Public Policy of Organ Transplants* A Twentieth Century Fund Book San Francisco: Jossey-Bass, 1994; for Canada, see the Canadian Institute of Health Information *Directions* Volume 5(3), October 1998 "Highlights of 1998 Annual Report: Organ Donations not Keeping Pace with Demand" from the 10th Annual Report of the Canadian Organ Replacement Register (CORR).

been suitable donors as reasons for insufficient supply.⁴¹⁷ What dominated the public discourse, however, was the view articulated by transplant expert Jeffrey Prottras that “it is certain that many more potential donors still exist.”⁴¹⁸ Advocates pointed to costs, professional attitudes, inadequate recognition of donor families and public attitudes as barriers to a higher donor rate.⁴¹⁹ On this basis, media stories spoke of the “alarming number of patients who die waiting” and defined the organ shortage as a “public health crisis,” to justify the intensification of efforts to improve the system.⁴²⁰

4.3.1 *The Problem of Ignorance: Public Campaigns*

Investigating the reasons for the organ supply shortage, research conducted by organ procurement organizations in the United States found that public opinion polls showing widespread public support for organ donation did not convert into the practice of signing donor cards or giving next-of-kin consent.⁴²¹ To correct this discrepancy, “donor recruitment” campaigns were launched to raise awareness of the importance of signing legal consent in life. Such efforts were led by OPOs in conjunction with the increasing number of non-governmental organizations now considered part of a “transplant community.”

To reduce ignorance of the ability to donate one’s body, the Boys Scouts of America launched a Donor Awareness Program in 1989 in cooperation with the American Council on Transplantation.⁴²² Renée C. Fox and Judith Swazey document this effort by recounting the social marketing techniques used to encourage citizens to exercise their sovereignty to make a choice to donate or not while alive. Major American newspapers ran full-page ads with tear-out donor cards to publicize a “Donor Awareness Patch” Scouts could earn if they discussed organ donation with their family. Becoming more aware of what organ donation is and “how it can benefit the lives of others” was the

⁴¹⁷ Reasons for fewer automobile crashes given include seat belt laws, infant car seat laws, helmet laws of motorcyclists, higher minimum drinking age and enforcement of drunk driving laws. “The Shortage of Organs: Reasons and Solutions” London Multiorgan Transplant Service <http://www.lhsc.on.ca/transplant.orgshort.htm>

⁴¹⁸ Jeffrey Prottras, 1994. *op.cit.* p. 42.

⁴¹⁹ London Multiorgan Transplant Service website. *op.cit.*

⁴²⁰ Fox and Swazey, 1992. *op.cit.* p. 45.

⁴²¹ Schmitz and Gray, 1993. *op.cit.* p. 19.

⁴²² Fox and Swazey, 1992. p. 57.

goal of the campaign. Although consenting to donation was not required to get the patch, Scouts were told, “it’s worth doing.” Just telling others of the “thousands who are waiting” and wearing the patch would “let people know your heart is in the right place.”⁴²³

The Scouts campaign emphasized speaking to one’s family to prevent next of kin exercising a veto over individual consent. Contrary to *Gift Act* provisions, hospital medical staff had developed a practice of asking for consent and not proceeding when next of kin object to the removal of all or specific organs (such as the eyes or heart) even when “a document of gift” indicated individual consent. To avoid family objection, a secondary message of individual right was included in campaigns like the Boy Scouts’.

Throughout the 1990s, other campaigns encouraged the creation of the ideal donation situation whereby individual right is conceded to by otherwise objecting family members based on discussions of death in life. Driver’s license consent forms were thereby modified to add a statement at the bottom: “When you sign this card, please talk it over with your family and ask them to respect your wishes.” Brochure slogans to “share your life, share your decision” were also added to convey this message. Encouraging citizens to conduct an “Organ Donation Discussion” with their family, the provincial OPO website (M.O.R.E.) offers “tips to help you and your loved ones overcome any concerns you may have so that you can talk about organ donation in a meaningful way.”⁴²⁴

Taking a legislative approach to address the demand-supply gap, the British Columbia Legislature unanimously passed amendments to the provincial *Human Tissues Gift Act* in 1997. The OPO of this province (the BC Transplant Society) described the intention of these changes “to ensure that all families of ‘potential donors’ are offered the opportunity to donate life-saving and life-enhancing organs, tissues and eyes...to assist British Columbians awaiting life-saving transplants.”⁴²⁵ The new regulations were designed to increase organ and tissue donation in British Columbia through a series of measures such as making individual organ donor registration a ‘living will’ *to be shown*

⁴²³ *Ibid.*

⁴²⁴ http://www.transplant-ontario.org/family_discussionf.html

⁴²⁵ http://www.transplant.bc.ca/issues_universal.html

to next of kin upon 'brain death'. It is only if the relative can produce evidence to prove to the "Designated Requestor" at the hospital that the individual had changed their mind that individual consent can be overridden.⁴²⁶

Paradoxically, moving the end of personhood to an earlier point in the diagnosis of 'brain death' is countered by an extension of the rights of personhood – through individualism - granted to patients classified as 'potential donors'. Diminishing the role of the family gives next of kin possession of "their loved one" only once they are no longer of value to society. Also absent, in presenting the choice to donate or not, is any notion of a right to decide what constitutes one's death.

Metaphysics of Meaning

The attribution of meaning given to transplantation through donor recruitment campaigns is designed to instill the moral obligation to donate while avoiding questions of the appropriateness of asking for gifts, what kind of creditor-debtor bonds form through this kind of transfer,⁴²⁷ dependency or existential questions about nature, persons, self/body integrity and individuality. For OPOs who conduct these campaigns, the metaphor of the "gift of life" is used as a tool to enrol citizens into the 'truth' of the discourse of donation. In addition to messages directed at consent rules, campaigns typically contain three central characteristics: establishing the need for organs, demonstrating that those in need (the organ-dying) are deserving and that those who receive are grateful (implying that it works). Often this is presented in the same "strong rhetorical framework" of a "simple dichotomy of life versus death" for the organ-dying displayed in the 1980s.⁴²⁸ Claims of fact and empathy for one set of dying patients forms the basis for offering means and a reason to help. In the abstract, people can take an ethical stance in favour of alleviating this form of suffering by signing a consent card. Motivations to do so include knowledge of saving the life of someone else and comfort in grief, as a means of responding to the unexpected tragedy of 'brain death'.

⁴²⁶ *Ibid.*

⁴²⁷ This has been the subject of research by Fox and Swazey, 1978 and 1992. *op.cit* see also, Laura A. Siminoff and Kata Chillag, "The Fallacy of the 'Gift of Life'" *Hasting Centre Report* 29(6): 34-41, 1999.

⁴²⁸ Alonzo L. Plough, 1986. *op.cit.* p. 117.

One example that follows this pattern is a brochure produced by The Mutual Group Insurance Company entitled "Breaking Barriers to Organ Donation." It opens with a parent sharing his story of having to decide.

When we consented to Vic becoming an organ donor, we knew it was going to change the quality of life for somebody. The people who received transplants because we made that decision will live their lives more fully - that's a good feeling.⁴²⁹

Donation is thus presented as a positive act on the grounds that it enables a response to tragedy. This action does not diminish the first death - that of the donor - but enhances its meaning by making something good out of something bad. Donation is thus presented as a new means to grieve the loss of a child's sudden death. The story continues as the parent states that although Mel Davis's 25 year old son died, six people became organ recipients as a result. The next panel quotes an appreciative recipient: "I think about the family, and the donor everyday...If they hadn't said yes, I wouldn't be here today." After pointing to the two donor cards attached, the final panel is a picture of a seven-year old girl accompanied by a narrative of empathy and unfairness that she is ill. An organ would restore her to health and normality, in fact, "her future depends on the availability of a suitable donor."⁴³⁰

This economy of meaning illustrates Nikolas Rose's observation that "medicine has become saturated with questions concerning the meaning of life" as well as the way in which "we have come to rationalize our fate in medical terms" and in terms of our medical choices rather than "God's will."⁴³¹ Another example is a quote from a "donor family" posted on the Ontario OPO (M.O.R.E.) website: "The Bowers now unconditionally believe that organ donation gives meaning and purpose to human life!"

'Being Jenna-Marie's mother gave me extreme joy. Being the parent of a child who died, was the most difficult thing I have had to endure in my life. In contrast the act of donating her organs was one of the most profoundly moving and strangely wonderful experiences I have had. Nothing could change the outcome of

⁴²⁹ http://www.transplant-ontario.org/donors_stories_2f.html

⁴³⁰ *Ibid.*

⁴³¹ Nikolas Rose, 1994. *op.cit.* p. 69.

our accident. Fortunately for my family we had the opportunity to make Jenna-Marie's outcome help others.⁴³²

The father in this case wrote that although they lost their daughter, "today we have three children, Bryson, Trent and Elyse; a family that collectively rejoices in a renewed life, thanks to organ donation."⁴³³ From an anthropological perspective, what participating in transplantation led to for these people are new familial relations; from a metaphysical point of view, it is medicine that provided a "rational, secular and corporeal solution" to "how we might make the best of our life by adjusting it to our truth."⁴³⁴ Once the couple accepted the truth of 'brain death', it was the enlightened decision to allow medical intervention on the insignificant remains of their daughter for the sake of others that provided a way for them to cope with their loss.

Organs are often described as "supreme gifts" with which the donor "literally gave of themselves for others." Organs thus remain - like gifts - inalienable from persons. "Donors" and their families who give consent are thus ulogized as ethical subjects - not objects. A t-shirt printed by the Organ Donor Awareness Committee at London's Multiorgan Transplant Service shares the slogan, "Don't Take Your Organs to Heaven...Heaven Knows We Need Them Here."⁴³⁵ The Cartesian view of the body as "a biological substratum of no relevance once the soul ceases to 'use' it" affirms that giving away something no longer needed is not a sacrifice.⁴³⁶ This draws upon the conceptualization of the body as a "gift," the value of which comes through giving. The implication that it is selfish to bury organs, dismisses the view that organs, as the body of the person, *is* the person rather than what they possess.

Throughout donor recruitment campaigns runs a narrative of personhood, constructed through the presentation of the donor as an ethical subject rather than an object. The exercise of subjectivity is captured in the language of 'giving' which is chosen instead of 'taking' or 'being used'. Even though it is the number of organs that have assumed a salience, by not asking directly for organs publicity is careful to convey

⁴³² http://www.transplant-ontario.org/donors_stories_2f.html

⁴³³ *Ibid.*

⁴³⁴ Nikolas Rose, 1994. *op.cit.*

⁴³⁵ "Ethical Issues" London's Multiorgan Transplant Service. <http://www.lhsc.on.ca/transplant>

⁴³⁶ Gerald McKenny, 1997. *op.cit.* p. 199.

the message that it is the meaning of the gift rather than the object itself that is of value. Assume the status of 'intended donor' is requested instead: "Please make your decision to become an organ donor."⁴³⁷ It is also awareness - not getting organs - that is stated as the goal of donor recruitment campaigns. To endorse and ensure citizens remember the organ-dying, *Bill-C 202* passed in Canada's House of Commons in 1997, declared the last week of April National Organ Donor Awareness Week⁴³⁸ Since it cannot be known who will suddenly begin to die brain-first, the project to register more citizens as intended donors is necessarily continual.

Range of Allies

Working on campaigns by speaking on the radio, staffing mall displays and even transporting organs are paid staff of organ procurement organizations or hospitals and volunteers. Members of the public who participate are patients on the transplant waiting list, live donors, family members of an organ-dying person, donor families and members of the general public.⁴³⁹

The BC Transplant Society has a network of volunteers throughout British Columbia all dedicated to helping increase awareness of organ and tissue donation and transplantation. Volunteers help spread the word by participating in health fairs, community events, and public speaking programs.⁴⁴⁰

Adding credibility to the effort, campaigns are supported by disease groups such as the Kidney Foundation of Canada, the Heart and Stroke Foundation, the Canadian Liver Foundation, the Lung Association and Canadian Cystic Fibrosis Foundation as well as organ storage facilities such as the Eye Bank of Canada. The B.C. Transplant Society is sponsored by Rainbow Press, The Province and The Vancouver Sun newspapers, Save-on-Foods and Overwaitea grocery store chains, Roche pharmaceutical company, London Drugs, Global television and CKNW radiostation.⁴⁴¹ To work on the new legislation in 1997, the provincial Ministry of Health worked collaboratively with numerous allies of

⁴³⁷ http://www.transplant-ontario.org/family_discussionf.html

⁴³⁸ <http://www.lhsc.on.ca/transplant/orgshort.htm>

⁴³⁹ http://www.transplant.bc.ca/volunteer_life.html

⁴⁴⁰ *Ibid.*

⁴⁴¹ http://www.transplant.bc.ca/programs_sponsors.html

“organ donation”: the provincial OPO, the Health Association of BC, the BC Medical Association, the BC College of Physicians and Surgeons, the Registered Nurses Association and other associated groups.

Volunteers are often people who in their own encounters with medicine have come into contact with and found meaning in “organ donation.” Football star Walter Payton tentatively offered his way of coming to terms with his illness and need for an organ as an unforeseen legacy: “maybe this is my way of making other people aware of some of the needs in the world.”⁴⁴² Similarly, conducting media interviews, writing letters and encouraging friends and relatives to sign donor consent cards allowed one set of parents to find comfort and accept that their child was dying. “At least we knew that we were doing all we could for Janice.”⁴⁴³ Joining or starting new donor recruitment campaigns to try to “do something about the shortage of organs” becomes a way to preserve themselves, or their kin’s life. “Recipients”/chimeras are also encouraged to join support-groups to find commraderie in the trials and tribulations of post-transplant surgery recovery. One activity such groups often participate in are “donor recruitment campaigns.” The presence of recipient/chimeras provides “living proof” that transplantation works to demonstrate efficacy of this therapeutic modality. It is promoted for the beneficiaries of “organ donation” as a way of thanking donors, but is ultimately self-serving in not working to decrease the means by which brain-dying patients die but the way in which other - and they, if a retransplant is required - will die.⁴⁴⁴ The pursuit of organ donation as a cause positions it as a secular ethical regime in which thousands of average and extraordinary people have enroled. For all who stand within this ‘truth,’ transplantation is equated with the morally praiseworthy act of donating. As a good act that averts death for others in sacrificing one, “donation” is necessary and unquestionable.

⁴⁴² Don Pierson, “Payton vows to put tears on hold” *Ottawa Citizen* February 8, 1999. p. B1.

⁴⁴³ Tat-Ying Wong “My daughter is dying” *CMAJ* 157: 172-4 (July 15, 1997)

⁴⁴⁴ Siminoff and Chillag, 1999. *op.cit.* p. 39.

4.3.2 *Reducing Negligence by Intensifying Surveillance*

In Canada and the United States, the “supply crisis” led to the intensification of hospital regulation. Audits of hospital records raised concerns regarding the rate at which ‘potential donors’ become ‘actual donors’. A more pointed targetting of medical professionals and hospitals as at fault for the continued shortage of organs led to new techniques and professional “turf wars” over the handling of patients dying brain-first. These changes were justified by the discourse of donation solidifying the claim of a moral imperative to increase the organ supply.

One reason given for the low “conversion rate” of potential to actual donors was the way in which families were asked for consent to donate the organs of their relative. Researchers argued that hospitals abiding by “routine request” rules may not succeed in obtaining organs if the request is not posed correctly. In addition to studies examining racial and ethnic minorities’ attitudes toward donation,⁴⁴⁵ a refined process of asking for consent from next of kin was developed. Instead of informing the family of the prognosis of ‘potential donor’ first (as instructed in the 1986 *Donation Services* guideline), a “donation coordinator” approaches the waiting family first to inform them of the diagnosis of ‘brain death’. A nursing text book instructs a “decoupled” step-by-step model based on a 1988-1990 study as preferable based on the temporal separation of conversations regarding ‘brain death’ and donation.⁴⁴⁶ “The family must be afforded time to fully understand what brain death is and what it really means before they can accept that their loved one is legally dead and supported only artificially by machines and medications.”⁴⁴⁷ Next, the family is allotted additional time to “see the patient, say their good-byes, and begin grieving the loss of the loved one.” The third and final step, now that the family has had time to accept the finality of ‘brain death’ and have separated from “their loved one and now must begin to make final arrangements to bring the experience to closure,” is the discussion regarding organ and tissue donation.⁴⁴⁸

⁴⁴⁵ See Mary S. Wheeler, and Alan HS Cheung “Minority Attitudes Toward Organ Donation.” *Critical Care Nurse* 16:30-35, 1996.

⁴⁴⁶ Julie Mull Strange and David C. Taylor “Organ and Tissue Donation” *Transplantation Nursing: Acute and Long-term Management* Marie T. Nolan and Sharon M. Augustine (eds.) Norwald, Connecticut: Appleton & Lange, 1995. p. 91.

⁴⁴⁷ Strange and Taylor, 1995. *op.cit* p. 89.

⁴⁴⁸ *Ibid.*

"Donation coordinators" are professional askers, designated to "introduce the concept of donation" with the purpose of obtaining consent to remove organs.⁴⁴⁹ By 1999, Canada's Sick Children's Hospital in Toronto, the Capital Health Authority in Edmonton and Royal Victoria site of the McGill University Health Centre had full-time "organ donation coordinators" on staff. These workers and nurses who work as part-time "co-ordinators" mobilize all intensive care staff in serving the brain-dying by trying to save their life while also serving the organ-dying by initiating the "donation process." As such they are responsible for the 'double medical gaze' positioning the patient as *subject* and *object*. They identify 'potential donors', raise the possibility of 'brain death', contact the provincial OPO and ensure that "donor maintenance" occurs. By keeping the body plugged in to circulatory and ventilatory machines so it does not "die," the shift in treating the patient as subject to object occurs while the "co-ordinator" seeks consent for donation from next of kin. Consent is thus, like 'brain death' declaration, just a step in the "donation process."

A second reason given for the low "conversion rate" was lack of knowledge by medical professionals on how to keep the body alive enough to be of use. Medical texts and articles on "donor management" techniques expressed concern about training professionals to minimize the "worrying" "consequences of brain death" on the quality of organs.⁴⁵⁰ Without perfusion maintained by ventilatory and circulatory machines, in the absence of energy from the whole body, organs will "die" and become unusable.⁴⁵¹ In the United States, one study found organs and tissues to be physiologically and structurally "improved" to " 'produce prime, quality organs'" as "standardized therapeutic tools usable in a variety of recipients."⁴⁵² Making organs more like universal parts requires medical intervention often lasting several days prior to organ removal. During this time bodies are "transformed relatively unproblematically into incubators for organs," and the

⁴⁴⁹ Canada, "Organ and Tissue Donation and Transplantation: A Canadian Approach" Ottawa: House of Commons, Standing Committee on Health, April 1999. p. xi, Glossary of Terms

⁴⁵⁰ M. Wilkening and M. Freysz "Brain Death: From Diagnosis to Organ Procurement" *Organ Transplantation and Tissue Grafting* P. Herve, G. Rifle, D. Vuitton, G. Dureau, P. Bechtel and E. Justrabo (eds.) London: INSERM/John Libbey & Co., 1996.

⁴⁵¹ Organs, such as the kidney, liver and heart, can regain function after a period of non-perfusion but to varying degrees.

⁴⁵² Linda F. Hogle, 1996. *op.cit.* p. 678-679.

machines connected to them must be monitored and adjusted constantly.⁴⁵³ This way of seeking to cure also became more entrenched as the range of medical professionals specializing in transplantation expanded. Instructions were published informing social workers, psychiatrists and nurse specialists on ways to better service organ-dying potential recipients by improving patient care within transplant centres and playing a part in raising the donor rate.⁴⁵⁴

Protecting the Right to Give

Public administration experts also began in the 1990s to write about how to alleviate the organ “shortage crisis” by elevating the role of organ procurement organizations. Within the express consent model, the territory of physicians in relation to OPO (“donation coordinator”) representatives was identified as a problem by American health policy analysts Arther Caplan and Jeffrey Prottras. Asserting a right of OPOs to access ‘potential donors’, they laid blame on “gatekeeper” physicians for “not giving every possible donor the chance to give.”⁴⁵⁵ The discretionary power of medical staff is in their opinion a weakness in the legal and political support for transplantation. In “fearful symmetry,” this stance parallels the lobbying efforts of the medical profession for cadavers in last century, examined in chapter two. For the benefit of society, physicians argued against the ability of directors of workhouses or hospitals to bury bodies rather than hand them over for dissection. Control over the dead denied anatomists their material. A century later, advocates for the organ-dying, concerned with barriers preventing increases in donor numbers, assert that “health care professionals need to be taught how to make requests, or if they are too discomfited by death, to yield authority over matters pertaining to procurement to others more adept at dealing with this harsh reality.”⁴⁵⁶

⁴⁵³ *Ibid.* p. 680.

⁴⁵⁴ For example see, Surjit Singh Dhooper *Social Work and Transplantation of Human Organs* London: Praeger, 1994 and John Craven and Gary M. Rodin *Psychiatric Aspects of Organ Transplantation* (eds.) Oxford: Oxford University Press, 1992.

⁴⁵⁵ Margaret Lock, “ ‘Organs: Donation or Routine Retrieval’ review of *The Most Useful Gift: Altruism and the Public Policy of Organ Transplants*” by Jeffrey Prottras, *Hastings Center Report*, January-February 1996: 41-42.

⁴⁵⁶ A.L. Caplan “Professional arrogance and public misunderstanding” *Hastings Centre Report* 18 (April/May): 34-37, 1988, p. 37, quoted in Fox and Swazey, 1992, *op.cit.* p. 63.

In his book, Prottras argues that even with “donor coordinators” in each intensive care unit, the basis of involvement of medical professionals paralleled that of “donor families” whereby participation is a matter of personal moral beliefs. Passage of “required request” and “routine inquiry” laws changed this to establish a necessity for involvement that permits external intervention in the relationship between physicians and the organ donor and family. As a move in the right direction, legislation serves to “socialize a previously private relationship and substitute policy for professional judgement.”⁴⁵⁷ However, such laws, and their goal to increase organs, are limited by “the interpenetration of the postmortem donation process with the premortem treatment and evaluations process.” Prottras states clearly that “in reality, the donation process cannot start only after the patient is dead. Death must be anticipated.” Hence, the challenge for OPOs trying to enforce “required request” laws, via their representatives in ICU, is the prohibition of intervention between a living patient and the doctor. Once the patient is declared ‘brain dead’, OPO agents can legitimately take action. However, the donation process optimally starts prior to death.

This allows the beginning of certain testing procedures involving the patient’s histocompatibility and identifying the presence of certain diseases, notably hepatitis and AIDS. *Plans for a brain death declaration must be put into effect before death*, as must plans to maintain the donor while permissions are obtained and logistics are worked out. Due to time restraints, a request for organ donation made without preparation at the time of death cannot be effectively acted on.⁴⁵⁸

This repeats the 1986 *Donation Services* guideline which emphasizes ‘potential donor’ categorization, not ‘brain death’ declaration. In spite of the *dividing practice* established in *Gift Acts* that two physicians uninvolved in the transplant surgery or with organ-dying patients must declare ‘brain death’, Prottras is explicit in identifying that “intrusion into the premortem domain of the physician is required.” The ability to treat the patient as an object while still a subject, “depends wholly on the physican’s sufferance.”⁴⁵⁹

Prottras concedes that patients are protected by the practice of allowing only medical considerations to play a role in their treatment. However, it is because patients

⁴⁵⁷ Jeffrey Prottras, 1994. *op.cit.* p. 103.

⁴⁵⁸ *Ibid.* (emphasis added)

⁴⁵⁹ *Ibid.* p. 105.

also have an interest in donation - which society has endorsed as a social right declared superior to "the competing and hitherto dominant values of professional autonomy" - that a role for considerations other than medical matters is just.⁴⁶⁰ Working on behalf of 'potential donors', OPOs and their network of representatives ensure that patients are not denied the opportunity to give through the negligence of medical professionals allowing their physical state to deteriorate such that their organs become unsuitable. In Arther Caplan's view, "routine request" legislation is a societal endorsement "that people routinely be given the option of organ and tissue donation as a last act of respect for the dead and their families and as an expression of concern for those who will die unless more organs and tissues are made available."⁴⁶¹

The desire to donate is thus argued to be so moral as to trump all other considerations. Referring to the dead as active agents still exercising sovereignty over their property - the body as a "gift" - Prottas and Caplan attribute to the 'living dead' a form of personhood abstracted from the treatment of their bodies. This further illustrates one of the way in which the "supply crisis" did not bring the *technology of health* or death of the donor into question; it served instead to intensify efforts to obtain organs through the assertion of a right to give.

"The System" Debate

In response to the continued failure of "the procurement system" to provide a sufficient number of organs to meet demand, surgeon-researchers (in some cases supported by biotechnology corporations or brokers) sought to create new sources of organs through changing the 'brain death' criteria for 'potential donors' or rules regarding sources. As referred to in chapters two and three, these efforts, made from 1984 to 1999, attempted to expand the donor pool by modifying the parameters of usage based on degree of 'sameness', degree of 'brain death' or death order. This included the use of marginal organ donors (over seventy and with certain illnesses),⁴⁶² anencephalic infants partially 'brain dead',⁴⁶³ artificial parts,⁴⁶⁴ "spare" parts of livers,

⁴⁶⁰ *Ibid.*

⁴⁶¹ A.L. Caplan, 1988, *op.cit.* p. 37, quoted in Fox and Swazey, 1992, *op.cit.* p. 63.

⁴⁶² Fox and Swazey, 1992. p. 45.

⁴⁶³ See discussion of anencephalic babies in chapter 3 and LRC "Procurement and Transfer of Human

lungs and bowels from living donors,⁴⁶⁵ “non-heart beating cadaver” patients who die heart first,⁴⁶⁶ primates,⁴⁶⁷ making organs from stem cells or genetically engineered pigs bred with human parts (xenotransplantation).⁴⁶⁸ Although largely unsuccessful, the desire to expand the pool of ‘potential donors’ is justified by the ‘truth’ that the “organ supply shortage” is the problem. Also notable is how the absence of criteria for death established in law in Canada means that changing the parameters around who is considered dead enough to be a ‘potential donor’ is not illegal. It is in response to threats to public safety from experiments mixing humans and animals that the federal government has been drawn into xenotransplantation research.⁴⁶⁹ The consequences of pushing the boundaries on who can be a source has come under criticism. In response to a protocol by the OPO of Illinois in 1993 for ‘non-heart beating cadavers’ whereby kidneys were perfused inside patients bodies without seeking family consent, Renée C. Fox describes the “seeming willingness to use any means to fulfill its sense of mission about obtaining organs” as originating from “an evangelical attitude toward transplantation, combined with zealotry about procuring organs.”⁴⁷⁰

Another route to increase supply that some experts started advising in the 1990s was to change the rules by removing the ban on using living, unrelated kidney donors. In 1990, a study of the mortality rate among a group of male Arab “recipients” who travelled to Bombay to received new kidneys was published in the medical journal *The Lancet*. Without mention of the long-term health of the donors, the article stated that donors received “rewarded gifting” or “compensated gifting.” All impoverished shantytown dwellers outside Bombay, the donors were “rewarded” \$2,600 to \$3,300 for

Tissues and Organs” Working Paper 66, 1992. p. 95-106.

⁴⁶⁴ Bert Hill, “WorldHeart readies for business” *Ottawa Citizen*, January 6, 2000. *op.cit.* (See chapter two, footnote 121)

⁴⁶⁵ David Roberts, “Lung donors come to niece’s aid: Manitoba Cree brothers gladly donate organs for rare and risky transplant” *Globe and Mail*, January 26, 2000. p. A1.

⁴⁶⁶ Graham Campbell and Francis R. Sutherland “Non-heart-beating organ donors as a source of kidneys for transplantation: a chart review” *CMAJ* 1999; 160: 1573-6; John B. Dossetor “Death provides renewed life for some, but ethical hazards for transplant teams” *CMAJ* 1999; 160: 1590-1

⁴⁶⁷ Dr Gill Langley and Joyce D’Silva, 1998. *op.cit.* (See chapter 2, footnote 123)

⁴⁶⁸ Canada, “Report of the National Forum on Xenotransplantation,” 1997. *op.cit.* (See chapter 2, footnote 195)

⁴⁶⁹ See Linda Pannozzo, “The Little Piggy’s Going to Market” *This Magazine*, Vol 3(1), July/August 1999. p. 34-39.

⁴⁷⁰ Renée C. Fox “Afterthoughts” 1996. *op.cit.* p. 267.

the inconvenience of kidney amputation and loss of earnings during recovery. Authors of *The Lancet* article argued that financial incentives may be considered “‘moral and justified’ on the grounds that ‘kidney donation is a good act. It is a gift of life’.”⁴⁷¹ In 1998 a debate was sparked in Canada when a group of prominent doctors and ethicists, speaking for the International Forum for Transplant Ethics, argued that *Gift Act* rules should be changed to allow the sale of non-vital organs.⁴⁷² In the United States, “financial incentives” have been introduced on a trial basis in Pennsylvania.⁴⁷³ Reports of black markets in other poor countries and the use of organs taken from either executed or “voluntary” living prisoners for international trade also emerged in the late 1990s.⁴⁷⁴

In response to these developments, experts from the fields of medicine, law, ethics and economics entered into the debate by publishing articles regarding the necessity to either: intensify surveillance of hospitals and secure consent from more citizens; classify more patients/animals as ‘potential donors’; or move to a monetary system. For example, some economists argued that “monetary remuneration provides greater incentive to transfer organs than do purely altruistic motives.” Others devised economic schemes ranging from mutual insurance pools to futures markets.⁴⁷⁵ By asking “what legal reforms, if any, should be instituted to alleviate perceived tissue scarcity?” the premise of academic debate has been to adopt the truth claim of the discourse of

⁴⁷¹ Nancy Scheper-Hughes, *Death Without Weeping: The Violence of Everyday Life in Brazil*, Berkeley: University of California Press, 1992. p. 237-238.

⁴⁷² J. Radcliffe Richards, A.S. Daar, R.D. Guttman, R. Hoffman, I. Kennedy, M. Lock, R.A. Sells and N. Tilney, writing for the International Forum for Transplant Ethics, “The case for selling human organs: A group of prominent doctors and ethicists argue we should reconsider our ban on the sale of non-vital organs.” *Ottawa Citizen* July 6, 1998. p. A11 reprinted with permission from *The Lancet*, Jane Coutts, “Exchanging kidney for cash criticized: Head of B.C. Transplant Society says there are better, fairer ways to deal with organ shortages” *Globe and Mail* July 7, 1998 p. A6; Nicolass Van Rijn “‘Kidneys for sale’ plan starts and uproar: Opponents slam call for trade in transplant organs” *Ottawa Citizen* July 8, 1998. p. A1.

⁴⁷³ Sheryl Gay Stolberg, “Pennsylvania to give ‘reward to families of organ donors: Program of giving cash toward funeral costs will be carefully scrutinized for ethical and legal implications” *Globe and Mail* May 7, 1999. p. A11.

⁴⁷⁴ See Andrew Higgins “Death-row organs ‘for sale in US’” *The Guardian* Wednesday, February 25, 1998. p. 12.; Rothman, David J. “The International Organ Traffic” *The New York Review* March 26, 1998. p. 14-18.; Rothman, D.J., E. Rose, T. Awaya, B. Cohen, A. Daar, S.L. Dzemeshevich, C.J. Lee, R. Munro, H. Reyes, S.M. Rothman, K.F. Schoen, N. Scheper-Hughes, Z. Shapira, H. Smit. 1997. “The Bellagio Task Force Report on Transplantation, Bodily Integrity, and the International Traffic in Organs.” *Transplantation Proceedings* 29:2739-2745.

⁴⁷⁵ Gloria J. Banks “Legal and Ethical Safeguards: Protection of Society’s Most Vulnerable Participants in a Commercialized Organ Transplantation System” *American Journal of Law and Medicine* Vol. 21(1): 45-110, 1995. p. 77.

donation that body parts are needed and their provision necessary.⁴⁷⁶ The crux of the debate on the need to change the criteria for 'potential donors' or rules regarding sources is whether the "procurement system" established according to *Gift Acts* can be blamed for the "shortage problem" and what changes will increase organs.

Often giving the rationale that more organs can be found from 'brain dead' humans, recommendations to reject new sources or rules add greater pressure to produce more natural resource bodies through the express consent model. More importantly, however, is that debate about "the system" further 'black boxes' transplantation as a *technology of health* and the death of the donor by "not questioning the obvious, and building the questionable upon the unproblematic."⁴⁷⁷ Given the strength of the association supporting the truth claim that organ shortage is the problem, the only question is how to get more. Lone critics, such as Nancy Scheper-Hughes who argued that "it's a scarcity that can never under any circumstances be satisfied, for underlying the need is the quintessentially human denial and refusal of death," are too weak to challenge 'truth' continually reasserted in academic and government circles.⁴⁷⁸

4.4 Canada's "Shame"

To respond to the organ supply problem, federal and provincial governments in Canada began investigating three aspects of transplantation: the safety of organs and tissue transfers, the feasibility of xenotransplantation and the organ procurement system.⁴⁷⁹ In response to a report submitted to Health Canada in 1995, by the lobby group Organ Sharing Canada, the provincial deputy ministers of health asked the Federal/Provincial/Territorial Advisory Committee on Health Services (ACHS) to review organ and tissue donation.⁴⁸⁰ In September 1996 a 13 point national strategy for

⁴⁷⁶ LRC "Procurement and Transfer of Human Tissues and Organs" Working Paper 66, 1992.

⁴⁷⁷ *Ibid.* p. 222, footnote 2.

⁴⁷⁸ Nancy Scheper-Hughes, "The New Cannibalism," 1998. *op.cit.* p. 14.

⁴⁷⁹ Canada, "Report of the National Consensus Conference on Safety of Organs and Tissues for Transplantation," 1995. *op.cit.*; Canada, "Report of the National Forum on Xenotransplantation," 1998. *op.cit.*; Canada, "Proposed Risk Management Framework to Address the Safety of Tissues and Organs for Transplantation in Canada," 1998. *op.cit.*

⁴⁸⁰ "Organ and Tissue Donation and Transplantation: A Canadian Approach" Report of the Standing Committee on Health, April 1999. *op.cit.* p. 14.

improving donation and distribution led to an implementation plan a year later complete with timeframe and cost analysis. Also in 1997 a National Coordinating Committee on Organ and Tissue Donation and Distribution was appointed and asked to conduct research on the implementation requirements for the 13 points. As a permanent committee, organ donation was given priority at the senior government level. In addition to five governmental members from across Canada, five representatives of the transplant community sit on this committee: The Canadian Transplant Society of transplant surgeons, Canadian Association for Transplantation of allied professionals, Canadian College of Health Services Accreditation, Kidney Foundation and Canadian Institute of Health Information (who manage the Canadian Organ Replacement Register).⁴⁸¹ Aligned as allies in the effort to increase organ donation as well as ensure public safety in receiving transplants, this group of stakeholders are continually invited to attend government conferences and consultation exercises.

To direct public policy, measurements of demand and supply collected through the Canadian Organ Replacement Register allowed for an overview of the number of organs being transferred in Canada's "economy" in body parts. Between 1988 and 1994, the demand for organs in Canada increased over 200% while the actual number of transplants performed increased by 40% from 1988 to 1998. There was nonetheless a decline in the number of transplants performed by 1% each year between 1988 and 1994.⁴⁸² In 1992, 330 people became cadaveric "organ donors." In 1995 this number was 436. But in 1996, only 423 people became "donors" representing a 3% decrease in the number of cadaveric organ donors.⁴⁸³ Thus, donors declined as the number of patients waiting for an organ grew at an average annual rate in the 1990s by 9%.⁴⁸⁴

The decline in the Canadian "donor rate" was explained by the Co-chair of the National Coordinating Committee on Organ and Tissue Donation and Distribution,

⁴⁸¹ Stakeholders include: Canadian Organ Replacement Register, Canadian Society for Transplantation, Canadian Society for Transplantation Co-ordinators, Canadian Council on Hospital Accreditation and the Kidney Foundation.

⁴⁸² Canada, "Proposed Canadian Standard for Xenotransplantation" July 1999. Ottawa: Health Protection Branch, Health, p. 1.

⁴⁸³ Canadian Institute for Health Information (CIHI) *Directions* Volume 5(3), October 1998 "Highlights of 1998 Annual Report: Organ Donations not Keeping Pace with Demand" from the 10th Annual Report of the CORR p. 4.

⁴⁸⁴ *Ibid.*

transplant surgeon Dr. Philip Belitsky as “not a reflection of the generosity of Canadians, but rather a testament to the lack of co-ordination in the organ-retrieval field.”⁴⁸⁵ At the 17th World Congress on the Transplantation Society, it was noted that unless donation increases, recipients could not benefit from the dramatic advances in transplant technology. Only a sustained, national initiative could turn around Canada’s record for donations which ranks among the worst in the Western world.⁴⁸⁶

The creation of a “national donor rate” made international comparisons and rankings of countries based on organ supply possible. On this basis, a series of articles from 1997 to 1999 began to repeat the message that Canada has a low “donor rate” relative to other countries. This originated with an article in the *Canadian Medical Association Journal* stating that “Canada’s donor rate is among the lowest in the industrialized world.”⁴⁸⁷ “Lagging far behind” the United States and Spain, “Canada’s per capita organ-donation rate was 44 percent lower than Spain.” An article in a national newspaper in July 1998 cited evidence that Canada’s organ donor rate lay at 13 per million compared to Spain at 26 per million.⁴⁸⁸ The *Journal* article implied that the supply problem caused 587 deaths “by waiting list.” Measuring per million rather than by death order furthered the impression of earlier statistics that there are enough people dying, just not enough giving. Such evidence regarding citizens presented as ‘fact’ appears to “act upon them in order to produce certain ends.”⁴⁸⁹ Repeated consistently with respect to concern over the “growing gap” between supply and demand, was the message that “any jurisdiction that gets serious about organ retrieval and distribution can usually chalk up improvements in its donation and transplant rate.”⁴⁹⁰ The gap between the 77 percent of Canadians who stated in a poll that they would donate their organs after death and only 58 percent who had signed donor cards was interpreted as an indication of lack of awareness.

⁴⁸⁵ André Picard, “Supply lags demand in organ transplants” *Globe and Mail* July 15, 1998. p. A3.

⁴⁸⁶ *Ibid.*

⁴⁸⁷ Nicole Baer “Canada’s organ shortage is severe and getting worse” *CMAJ* 157: 179-82, 1997.

⁴⁸⁸ André Picard, “Supply lags demand in organ transplants,” 1998. *op.cit.* and CIHI “Organ Donations not Keeping Pace with Demand,” 1998. *op.cit.*

⁴⁸⁹ Nikolas Rose, 1994. *op.cit.* p. 58.

⁴⁹⁰ Richard Addis, Editor, “Organ donations: Solutions, solutions: We can both encourage generosity, and develop xenotransplants” *Globe and Mail* Monday, March 8, 1999.

Frustrated with the slow pace of the National Coordinating Committee on Organ and Tissue Donation and Distribution, a public speaker for the organ donation cause, Member of Parliament for Esquimalt - Juan de Fuca and physician Keith Martin of the Official Opposition (the Reform Party), presented a motion to the House of Commons. With unanimous consent Motion 222 passed on October 9, 1997. It proposed four steps "to address Canada's organ donation problem" by improving the procurement system: implement a national real time database, remove financial disincentives to procurement in hospitals and "bring in legislation to protect the rights and wishes of those who, upon declaration of brain death diagnosis, have previously consented to donate their organs."⁴⁹¹ Also included was a "national mandated choice strategy" whereby every Canadian would be forced to make a choice for or against donation, with their answer recorded in a national database. As with President Reagan, the political party most in favour of the neo-liberal economic model of privatization and small government came forward as the strongest voice in favour of "organ donation."

When the House of Commons Standing Committee of Health followed up on implementation of the motion, the committee received a request from the Minister of Health, the Honourable Allan Rock, requesting advice on an appropriate role for the federal government.⁴⁹² The rare consensus among committee members representing five different political parties led to an agreement to conduct the "Study of the State of Organ and Tissue Donation in Canada." On her way to testify at the House of Commons Event, BC Health Minister Penny Priddy captured the spirit of good intentions and determination to solve a problem that required immediate attention.⁴⁹³ She informed a press conference held by the BC Transplant Society that "There is no question that people, including children, are dying every day in this country because of the lack of suitable organs...there is a critical need to increase the supply of organs for transplant in order to save as many lives as possible."⁴⁹⁴

⁴⁹¹ Motion M-222 printed in Journal no. 014, House of Commons of Canada, 36th Parliament, 1st Session, Thursday, October 9, 1997.

⁴⁹² "Organ and Tissue Donation and Transplantation: A Canadian Approach" Report of the Standing Committee on Health, April 1999. *op.cit.* p. 1.

⁴⁹³ *Ibid.*

⁴⁹⁴ British Columbia Ministry of Health, press release (1999:109) by Minister of Health Penny Priddy "National Organ Donor System would reduce waits, save lives: Priddy" March 9, 2000.

In this way, the emphasis on donation has had the effect of casting the death of the donor - death brain-first - as an act of nature and the death of a potential recipient - death organ-first - as cultural. Only the latter is a preventable death depending on the choices made in response to the former death. By contrast, this is not how the media or experts have presented transplantation in Japan. Margaret Lock describes a three hour documentary on 'brain death' and organ transplantation in 1990 focussed almost exclusively on the first patient and their life/death status.⁴⁹⁵ It also showed in graphic detail what Western audiences never see: the dismemberment of a young woman undergoing surgical removal of seventeen organs, from the heart to large sections of bone, joint, and muscle tissue. Her parts were put into boxes of dry ice for computerized distribution across the country with the last shot showing what was left of the body as nurses prepared it for burial. Other parts of the program such as the inclusion of scientific research on the possibility of restoring brain function and cases of patients who "came back to life" no doubt contribute to Lock's opinion of it as portraying an overall bias against the acceptance of 'brain death' as the end of life.⁴⁹⁶ The attention and concern regarding patients dying brain-first in this country clearly finds its match, however, in the West where attention to the needs of the organ-dying potential recipient are so dominant that what happens to the donor is excluded.

4.5 Conclusion: The Transplant Episteme

From the fragile visions of early transplant surgeons in 1968, access to brain-dying patients was accomplished through a discourse of donation that was encoded in law, enroled average and powerful actors, and embedded into routine medical practice. It became possible to speak of organs without mention of persons through the detachment and abstraction of personhood from embodiment. This was initiated through *Gift Acts* that granted "the body" quasi-object "gift" status followed by public pleas for organs taken up and advanced by powerful American politicians. The lexicon of "donation" in

<http://www.hlth.gov.bc.ca/cpa/newsrel/1999/109.html>

⁴⁹⁵ Lock, Margaret "Deadly Disputes: Ideologies and Brain Death in Japan" in *Organ Transplantation: Meanings and Realities* Youngner, Fox and O'Connell, 1996. *op.cit.*

⁴⁹⁶ *Ibid.*

hospital guidelines mobilized medical professionals to co-operate in making the natural resource body as for the donor. From this point forward, popular knowledge of transplantation was continually articulated in terms of “organ donation” as a morally praiseworthy act of giving. Implicit in this way of speaking about replacing organs was to suggest that it is the possible for one’s organs to be no longer needed to oneself but to another. ‘Brain death’ was thus insinuated in promoting ‘donation’ to further ‘black box’ the complexities and controversies holding this ‘fact’ in place.

In moving transplantation forward as a means of seeking to cure justified on the basis of morality, the “procurement systems” put in place have nonetheless failed to provide an adequate supply of organs. Awareness campaigns, legislation to mandate the medical profession to fulfill a duty to treat patients as objects for others, new grieving rituals and a greater role for organ procurement organizations and “donation co-ordinators” have not ameliorated the shortage of organs nor brought this into question. Failure has only fuelled a “missionary-like ardor” among large numbers of health professionals, public leaders and recipients to do more, claiming the “tragic shortage of organs a moral crisis that condemns thousands to die waiting.”⁴⁹⁷ As this chapter has demonstrated, the reason transplantation as a *technology of health* has not come into question is a result of the way in which the discourse of donation - embedded in statistics and everyday practices - contains a normative commitment to the organ-dying, obscuring the necessity of death and death brain-first in providing a source of organs.

For a noble cause, the creation of terms instilling a desire to donate is shapes our expectations and to revises our obligations to each other by changing the “space of possibilities for personhood.”⁴⁹⁸ In identifying “opportunities” for being objects instead of subjects, medical professionals and a large proportion of citizens have participated in and assumed new roles in this means of interconnecting large populations with individual bodies. The paradox is that once categorized as ‘brain dead’, patients are ‘non-person’ enough for it to be legitimate to remove organs while their status as ‘potential donors’ grants them a false agency to “give” if they have given prior consent or their next of kin so choose. As this chapter has shown, it is the economy of representation through which

⁴⁹⁷ Donald Joralemon, 1995. *op.cit.* p. 342.

⁴⁹⁸ John Lachs, 1988. *op.cit.* p. 249 and Ian Hacking, 1986. *op.cit.* p. 229.

personhood has been separated from embodiment that has led to this way of conducting transplantation.

By 1999 numerous allies and resources stood within the ‘truth’ of the transplant episteme through their support of “organ donation.” Viewing this as an unquestionable and “unmitigated good way” to seek to cure, support for the need to increase the organ supply accepted the ‘black boxes’ of the *technology of health* and ‘brain death’ as death.⁴⁹⁹ The equation of saving the lives of the organ-dying with the supply of organs was so inseparable that to hold the position of being against transplantation came to appear to be against saving the ill from death. A failure to distinguish a humane desire from a particular means, positioned being in favour of “organ donation” “as a moral weapon to be used against transgressors of the group’s normative order or to convert the remaining isolated pockets of conceptual atheists or heathens.”⁵⁰⁰ It was within this way of thinking about and doing things that legislators commenced their study of “The State of Organ and Tissue Donation in Canada.”

⁴⁹⁹ Fox and Swazey, 1992 *op.cit.* p. 207.

⁵⁰⁰ *Ibid.*

Chapter Five Breaching Moment

What we are doing in declaring death is marking a point along the continuum of organic decline which involves a social choice...We cannot, therefore, adjudicate the conflict of criteria in anything less than frankly normative terms. The question to ask is not when death really occurs, but why we should draw the line between life and death at [a particular point]...Where we put it is a matter of choice determined by the beliefs, values, and circumstances of the community...The naivete of the realistic view...succeeds only in keeping the choice unconscious and hence uncriticized. The thought that we can discover the point of death conceals from us what we really do and thereby makes an intelligent examination of our activity impossible.⁵⁰¹

Based on the positive knowledge of an organ shortage crisis, particularly acute in Canada, the House of Commons Standing Committee on Health accepted the advice of the Minister of Health in 1998 to conduct a study of donation in Canada.⁵⁰² The rare consensus between the political parties in taking up this task indicates that all legislators stood 'in the truth' of the transplant episteme. Parallel to the 1984 U.S. Subcommittee on Investigations and Oversight hearings, the event served as "a means of both publicizing the problem and developing legislative solutions."⁵⁰³ At the first session, Ms. Elizabeth Barker, Co-Chair, National Coordinating Committee on Organ and Tissue Donation and Distribution, gave the estimate that in the next century up to 50 percent of surgical operations in large hospitals are likely to have something to do with the "medical miracle" of transplantation. Enabling progress, however, requires addressing the "chronic problem...of undersupply."⁵⁰⁴ Presenting lack of treatment as unethical, Ms. Barker stated that "every year people die because too few organs and tissues are available for transplantation."⁵⁰⁵ This repeated the "strong rhetorical framework" of a "simple dichotomy of life versus death," that shaped public hearings in the United States throughout the 1980s.⁵⁰⁶

⁵⁰¹ John Lachs, 1988. *op.cit.* p. 237, 239.

⁵⁰² House of Commons of Canada, The Standing Committee on Health, Pursuant to Standing Order 108(2). Study on "The State of Organ and Tissue Donation in Canada." Minutes and Evidence from meetings number 61-76, held between February 2- March 24 held during the 36th Parliament, 1st Session, posted at <http://www.parl.gc.ca/InfoComDoc/36/1/HEAL/Meetings/Evidence/.htm> (notes hereafter will give the meeting number, date for first footnote, numerical point in tape recording, name of the speaker and who they represent for first footnote)

⁵⁰³ Keith J. Mueller, 1989. *op.cit.* p. 348.

⁵⁰⁴ No. 61, February 2, 1999 (0915) Elizabeth Barker, Co-Chair and Director of Acute Care Programs, Nova Scotia Department of Health

⁵⁰⁵ *Ibid.*

⁵⁰⁶ Alonzo L. Plough, 1986. *op.cit.* p. 117. For the federal government, the study provided an opportunity

To powerfully convey the culturally-caused tragedy of people dying organ-first, individual citizens made a poignant cry for organs in the third session: those in need of organs to cry for help, 'recipient'/chimeras grateful for the 'gift of life' and those grieving a death that could have been avoided had a replacement been available. As in past public hearings,⁵⁰⁷ children were centre stage to powerfully convey organs as needed and deserved.⁵⁰⁸

The framework experts gave to personal stories was of ethical versus unethical procurement systems, taking up the "system" debates of whether *Gift Act* rules or the donor pool of 'brain dead' humans are a sufficient source (primarily considering the possibility of xenotransplantation). What was in question - how to increase supply - thereby took as unproblematic the truth claims and 'black boxes' of the transplant episteme. Speaking within the discourse of donation, the focus of the hearings was exclusive to the needs of the organ-dying. Dominating the agenda was the moral imperative to increase supply. As such, the truth of 'the way things are' foreclosed examination of all that transplantation entails. This included consideration of the death of the donor (See Appendix B for a summary of topics discussed at each meeting).

In the midst of the proceedings, the unexpected contact of the Committee by three dissenters and their testimony to legislators disrupted – if only briefly – the discourse of donation. This incident (along with other brief mentions of 'brain death' at the hearings) stands as a breaching moment that exposes the transplant episteme by opening up one 'black box' to reveal that it is human agency and the exercise of power through the construction and maintenance of a 'truth' that allows transplantation to proceed. Contacted by the dissenters, the Member of Parliament for Wanuskewin, Mr. Maurice Vellacott of the Reform Party, appeared to step outside the 'truth' to first raise the question of 'brain death' at the fourth hearing. Following this incident, three doctors, Dr. John Woo-Sup Yun, Dr. Ruth Oliver and Dr. Micheal Brear, came forward to speak against transplantation at the seventh of the fourteen hearings. Opening up the 'brain death' 'black box', these testimonies were more difficult to ignore. Nonetheless,

to consider playing a role in the provision of healthcare service.

⁵⁰⁷ See chapter two and chapter four.

⁵⁰⁸ Consistent with other publicity promoting donation, children were highlighted in media coverage of the Standing Committee study.

legislators sought and found a way to reinstate the ‘fact’ that ‘brain death’ is death in order to continue with the task of increasing the available supply of body parts. When presented to them at a public hearing, law makers collectively refused to entertain the possibility that a fundamental dimension of this therapeutic modality – the use of the dying - may be illegitimate.

The dissenters challenged the use of the dying for body part replacement by arguing that harvesting organs is wrong because ‘brain death’ is not the end of personhood. Although all three argued that the ‘brain dead’ are still alive, they did so in two different ways. In the first panel of the session, the first dissenter, Dr. John Woo-Sup Yun, challenged the taken for granted practice that medicine, using scientific measurement, is the form of legitimation appropriate to the determination of death. His argument exposed ‘brain death’ as a category between life and death. In the second panel, the second and third dissenters, Dr. Ruth Oliver and Dr. Micheal Brear, challenged the taken for granted assumption that a neutral, reliable diagnosis of the cessation of brain function is unproblematic. Together these criticisms called into question the assumption that transplantation is an unquestioned good.⁵⁰⁹ Since ‘brain death’ serves as the ‘obligatory passage point’ that makes use of a category of dying patients as a source for body parts legitimate, questioning this category of ‘non-persons’ could potentially bring the entire enterprise into question.

With the history of transplantation accounted for, this chapter addresses the question that has guided this thesis: how was it possible to marginalize a challenge to the central premise of transplantation - that brain death is death? Specifically, how was the ‘fact’ that donors are ‘non-persons’ upheld at the Standing Committee event when ‘brain death’ was directly and publicly challenged. Exposing the existence and strength of the transplant episteme, the argument made is that the ‘Great Divide’ Bruno Latour identifies as characteristic of Western culture was used to restore ‘brain death’ as truth by continually returning the question to one of accuracy. Each time an attempt was made to turn the attention of the Committee away from the organ-dying, or engage them in a philosophical legitimation of the use of the ‘brain dead’, a discourse of medicine/science was used to dismiss and deconstruct the counter-truth of dissenters. Science was

continually asserted as the only appropriate form of authenticity, where belief claims were expressed as truth and deference made to greater expertise and authority. It was possible to assert the 'Divide', and to even completely ignore the dissenters' testimony, due to the sheer weight of allies and resources in support of donation and therefore 'brain death' as death. This demonstrates that it was not a revelation of truth from an epistemologically privileged voice that allowed transplantation to continue. Rather, there was too much capital invested in this way of seeking to cure for it to be successfully challenged.⁵¹⁰ The firmness of enrolment and strength of the episteme are evident in this breaching moment.

This chapter analyzes the exercise of power captured in the exchanges at the Standing Committee on Health study regarding 'brain death' as a problem. As the event unfolded, an initial exchange on the question of the death of the donor affirmed 'brain death' as an 'obligatory passage point' to transplantation. This was followed by the dissenters' testimony and a later incident in which truth claims were once again asserted. Each session reveals the operation and utilization of the 'Great Divide' by witnesses and legislators. To conclude this chapter, how and why questioning this *technology of health* cannot be tolerated is analyzed.

5.1 'Brain Death' as Death?

On the fourth day of hearings, 'brain death' was raised by a organ procurement organization representative as not merely a step in the 'donation process', but as a problem. The perspective of each pro-donation witness who became engaged in this discussion was that scientific progress is bound to meet with barriers. At the February 11th meeting, Mr. Donald Langlais, Director of Québec Transplant, repeated a previous speaker's information that surveys show over 80 percent of people in favour of organ donation. To this he added the caution that "perhaps this should be verified."

Mr. Donald Langlais: With respect to organ donations, we believe that there is a lot of room for improvement....In Quebec, however, many people have a problem

⁵⁰⁹ Donald Joralemon, 1995. *op.cit.* p. 342.

⁵¹⁰ Stephan Fuchs, 1992. *op.cit.* p. 14.

with the notion of brain death. The topic of brain death is always brought up whenever we speak with groups.⁵¹¹

Mr. Langlais's answer to this was that, "Specific programs should therefore be set up to help people understand many fundamental aspects of the organ donation and transplant process." During the discussion period he informed the committee that,

Mr. Donald Langlais: Brain death can be a sensitive issue even for people working in hospitals. It is an easy concept to deal with. We will therefore be targeting it specifically in the next year with some of our activities.⁵¹²

When his opportunity for questioning arose, Mr. Maurice Vellacott, the Member for Wanuskewin, chose to centre his comments "on the term 'brain death'."

Mr. Maurice Vellacott: I hear of people who had in fact been declared "brain dead" but then later recovered, and I want some responses on that.

I found your acknowledgement in this area very frank, Mr. Langlais, when you admitted it is not an easy concept to deal with, and that even personnel in the hospital did not necessarily grasp it, or there was some uneasiness to some degree. I would have to say I appreciate what I perceive to be some humility and honesty on that issue, because frankly some medical people are very dismissive about that, and maybe that's part of the problem. If there's no reason to be concerned, then maybe there needs to be a respectful communicating of that to the public in ways they understand, from a lay point of view....

I recount this because I was in conversation just in recent days with a medical doctor who had been declared 'brain dead', and she recovered and then went on to do a psychiatry specialty. It was a very interesting story, and not the only conversation I'd ever had along these lines. She said to me, 'Had there been someone in the next bed who needed a heart, and had they harvested my organs prematurely, I'd not be alive today. I would not have gone on to do a psychiatry specialty hereafter, had they moved in on me, 'brain dead', and harvested organs.'

So first off, can you give me a definition in lay terms of what you understand or perceive brain death to be, communicable to me? Then secondly, how do you explain this kind of situation, with a diagnosis of 'brain death' and recovery later?⁵¹³

Each panel member who responded stated that brain death is a 'fact' that can be reliably diagnosed. Mr. Langlais explained,

⁵¹¹ No. 64, Thursday, February 11, 1999 (1050) Mr. Donald Langlais, Director of Quebec Transplant.

⁵¹² No. 64 (1115) Mr. Donald Langlais, Director of Quebec Transplant.

⁵¹³ No. 64 (1125) Mr. Maurice Vellacott, Member of Parliament for Wanuskewin, Member of the Reform Party, the Official Opposition.

Mr. Donald Langlais: You said that someone had been declared brain dead, but then came back to life. This year, I was asked to speak on a Quebec television broadcast, and then went back to study the issue. When someone is declared brain dead, he is taken to a harvesting centre. That is where the question of caution comes in. In Quebec, as in other provinces, I believe that death must be certified by two independent persons who do not communicate with each other. This is to ensure that the patient is in fact brain dead, and that organs are not harvested from anyone demonstrating brain activity of any kind. The procedures to determine brain death are very specific. I think our physicians are well able to certify brain death.

There could have been a situation where someone was believed brain dead while just being in a coma, but it certainly wasn't absolute brain death. At this point, to avoid that danger, we require two statements of absolute brain death before intervening and taking any organ whatsoever.

I'll let the doctors tell you about it, but I'd be surprised to hear that anyone being declared absolutely brain dead by two experts ever came back to life.⁵¹⁴

No mention is made of whether efforts to save life resume if the patient is not found to be 'brain dead' or how such protocols are enforced. Langlais dismisses the possibility of error by directing attention to administrative rules and the capability of physicians to make an accurate diagnosis. Dr. Norman Kneteman, a liver transplant surgeon and representative of Alberta's OPO, responded by declaring definitively that "brain death is death." He argued that this term should not be used any more since in Canada and the western world, brain death is our definition of death. "If your brain no longer functions, irreversibly, you are dead."⁵¹⁵ Given that this is not a debate, he stated that the real question is the truth of the diagnosis.

Dr. Norman Kneteman: The question is, how can you be 100% sure that your medical diagnosis of brain death is true? That's the issue you really address. There are anecdotal situations where someone has supposedly come back from brain death. There are none that are well documented, where the person actually accomplished what was related—that is, two independent physicians went through all of the required tests necessary to make a diagnosis of brain death.⁵¹⁶

Specifying that a deep coma is a situation different from brain death, Dr. Kneteman revealed that the prognosis of irreversibility is what really counted: "Brain death means

⁵¹⁴ No. 64 (1130) Mr. Donald Langlais, Director of Quebec Transplant.

⁵¹⁵ No. 64 (1130) Dr. Norman Kneteman, HOPE Program in Alberta, Director, Liver Transplantation.

⁵¹⁶ *Ibid.*

the blood supply to the brain is irreversibly lost.” No blood flow to the brain is confirmed by a whole series of tests and sometimes special observation using radiological X-ray imaging. The sign taken to indicate ‘brain death’ which marks the “point of no return” for this doctor is blood supply to the brain. He added that: “It is important that the idea is transmitted to the public that in those situations, a very careful diagnosis is made independently on two occasions, and is an extremely careful process,” as well as the dismissal that “we are unaware of anyone in that situation recovering.”⁵¹⁷ Seeking reassurance, the legislator interrupted to confirm:

Mr. Maurice Vellacott: So that's uniform across the province, across the western world, the fact of two of them? Nobody is moving in before two? That's in every province across the country and in the western world, to your knowledge?

Dr. Norman Kneteman: That's my understanding for across Canada.

The other transplant surgeon present added specific identifier modalities, however, by telling the Committee that misjudgement does take place. Moreover, contrary to Mr. Langlais's view, not all physicians who diagnose ‘brain death’ are qualified to do so.

Dr. John Jeffery: The medical criteria are quite explicit and have to be followed by two members who are experienced in that process, and the word ‘experienced’ is very important there.

I've been doing transplantation for 28 years now, and over the years I have seen a number of people called down to the emergency room, where there is a brain-dead individual, and they go and stand at the bedside and in 30 seconds say, ‘That person is not brain-dead.’ They haven't even done any formal testing. It's done by inexperienced people who are not qualified to do that.

Transplant programs are exceedingly careful to make sure that anybody who declares brain death is well qualified. We make sure doubly.⁵¹⁸

What appears to make organ removal acceptable to Dr. Jeffrey is the involvement of the transplant program in ensuring the expertise of physicians diagnosing ‘brain death’ and checking again before removing organs. Catching the admittance that transplanters are involved in diagnosing death, Dr. Norman Kneteman immediately added that by law “no one involved in the transplant program can in any way be involved in the diagnosis of

⁵¹⁷ *Ibid.*

⁵¹⁸ No. 64 (1130) Dr. John Jeffery, Head, Section of Nephrology, Manitoba Transplant Program

brain death, because clearly there would be the potential of conflict. That's uniform, and that's an important consideration as well."⁵¹⁹ The fourth witness, Bette Boechler, program manager from the Saskatchewan Transplant Program, did not respond.

None of the witnesses attempted to explain the case of recovery from 'brain death' or address Mr. Vellacott's comment that hospital staff are uneasy with this diagnosis. Their answers offered accounts of steps taken to ensure patients are correctly classified. Not yet satisfied, the MP pursued the question further by asking whether organ transplantation would be possible if we had not defined death as 'brain death' several decades ago.

Mr. Maurice Vellacott: ...would it be fair to say that if we had not moved and shifted to accept the theory coming up from the States, as I understand it, that brain death was synonymous with death—if we had stayed with the earlier definition of all the body systems shutting down—would there be such a thing as organ transplantation?...Had we not moved to the "brain death" definition being synonymous with death, would we even have the possibility of organ transplantation?

To this Dr. Kneteman responded,

Dr. Norman Kneteman: That's the situation in some countries, such as Japan, which only adopted brain death last year. Donation there occurs from living donors when possible.

Mr. Maurice Vellacott: So they're just doing kidneys and other things like that.

Dr. Norman Kneteman: And occasionally segments of livers. But we also have to understand that brain death was not developed for transplantation. Brain death was developed by neuroscience experts, because they had people in comas, and the question came up in terms of the family's interests and the medical care system's interests: When is that an irreversible process? No one wants their family member supported forever.

So the criteria to diagnose irreversible brain death were developed by neuroscience experts for that reason. They were then applied in transplantation as a very effective safety valve.⁵²⁰

As this implied that the diagnosis was not required but merely an extra precaution, Mr. Vellacott again asked whether he was correct to assume that 'brain death' is necessary to transplantation. At this point Dr. Kneteman replied: "Cadaveric organ donation would

⁵¹⁹ No. 64 (1135) Dr. Norman Kneteman

⁵²⁰ *Ibid.*

not be really a possibility without the concept and acceptance of brain death.” But, Dr. John Jeffrey, Head, Section of Nephrology from the Manitoba Transplant Program disagreed,

Dr. John Jeffery: Many centres from around the world are now exploring and actually using what are called non-beating-heart donors. These are people who have arrived in the emergency room, have had a cardiac arrest, and have not been resuscitated. If one can get those patients to the operating room very quickly, with their family's consent, one can remove organs from those. This is actually practised in Halifax right now, quite widely in England, and I think it will be one of the routes we have to explore in this country for increasing the number of organ donors.

As his final question, the legislator responded to this new information by clarifying whether ‘brain death’ was legally recognized.

Mr. Maurice Vellacott: Is Manitoba the only province in the country where there's an actual law on the books, as I understand it, and then the others, by default almost, followed suit with the law in Manitoba in respect to brain death? I know the medical associations have commonly accepted it from time immemorial, or for many years now, but if my understanding is correct....

You would know, in each of your respective provinces, whether there's a law on the books in terms of brain death. Manitoba does, I believe.

Dr. John Jeffrey: The law is that you are dead when a physician says you are dead. The law has left it up to the medical profession to decide what the criteria for death are. That was challenged in the Manitoba courts back in the 1970s. Brain death is accepted by law as being an adequate-

Mr. Maurice Vellacott: Okay, so it was upheld in law in Manitoba; I guess that's what I'm saying.

Dr. John Jeffrey: Yes, but it's not written into law.

Mr. Maurice Vellacott: That's right, and the others use that as a precedent and go with that in view of the Manitoba court decision. Is that correct?

Dr. John Jeffery: Right.

Mr. Maurice Vellacott: Thank you.⁵²¹

Opening the black box of ‘brain death’, this exchange on the fourth day of hearings reflects the fragile entities of thought and power that make it permissible for transplant surgeons to access the dying for use as a source of body parts. Responses of the two witnesses reflect actor-network theory's finding that when controversies flare up,

⁵²¹ No. 64 (1135) Dr. John Jeffery

language becomes technical.⁵²² The non-doctor asserted that the privileged epistemic position of physicians provides the assurance of absolute knowledge. Of the two doctors, Dr. Kneteman exerted that very authority bestowed upon him by simply stating that 'brain death' is a 'fact'. He contained the possible controversies of the diagnosis by re-asserting the 'black box': based on the rules, 'brain death' is either present or absent. If recovery were possible it would be in the literature. Administration and accuracy are the only 'real' questions; the scientific form of legitimation the only way of knowing that applies. Reducing questions to technical considerations came to an end, however, when he was forced to admit that his practice is entirely dependent upon the "concept and acceptance of brain death."⁵²³ Dr. Kneteman's attempt to 'purify' 'brain death' was also undermined by the other transplant surgeon, who reflected the ongoing heterogeneity of this group (evident at early transplant conferences) by responding in an entirely different way. Dr. Jeffery saw no harm in revealing that errors occur and that other categories of dying patients are being used as donors.

In this discussion, which foreshadowed the handling of the 'brain death' issue, the casual mention of 'brain death' as a problem by transplant surgeons and one OPO representative was accepted by all but one legislator who questioned the attribution of this problem to ignorance. 'Brain death' resonated with the Member from Wanuskewin due to his exposure to a counter-truth. By taking an alternative seriously, he had already taken a half step out of the network of truth holding the fact of 'brain death' in place. His lesser deference to medical authority, possibly informed by his religious identification as a Christian who formerly performed pastoral work in hospital settings, may have also contributed to his probe of a presumably unproblematic aspect of transplantation. However, this difference from other legislators may have also played a role in the failure to draw other Members of Parliament into this line of questioning. Proceeding on with 'real' issues, the 'black box' of 'brain death' was once again closed.

⁵²² Latour, 1987 *op.cit.* p. 21.

⁵²³ No. 64 (1135) Dr. Norman Kneteman

5.2 Dr. Yun: Challenging the Role of Medicine

The controversies, commitments and uncertainties of this 'fact' were more difficult to ignore three days later when the Committee devoted a entire meeting to ethical issues.⁵²⁴ All three dissenters were scheduled to present at this meeting alongside ethics experts, a rabbi and a professor of medicine in neurology who was summoned by the committee to appear.⁵²⁵ Divided into two sessions, the first one had four witnesses, including Dr. John Woo-Sup Yun; the second session had five witnesses testifying with Dr. Ruth Oliver first and Dr. Micheal Brear last. A structured discussion period, with time allotments for each legislator to ask questions, followed each set of presentations.

Opening the first session, Rabbi Reuven Bulka began by stating that "people in Canada die waiting for organ donations. Our pressing needs are not being met by the population at large."⁵²⁶ Addressing the agreed upon problem of "organ shortage," he called this a "major health challenge" and a "major moral challenge." To end this situation, Rabbi Bulka encouraged more promotional activities whereby politicians and religious leaders sign their organ donor card in a highly visible, public manner. He also argued for greater accessibility to consent through questions on tax forms, lottery tickets and passport applications, with the possibility of tax incentives to donate. Rabbi Bulka articulated why changing the rules may be necessary: "With the crisis we are facing – the critical shortage and the pursuant loss of precious life – we are forced to ask whether the present protocol of gaining family consent is justifiable."⁵²⁷

He was followed by Dr. Aaron Spital, Associate Professor of Medicine, University of Rochester and Nephrology Unit, who lobbied for "a plan designed to

⁵²⁴ Section 5.2 to 5.4 quotes from Meeting No. 67 Tuesday, March 2, 1999.

<http://www.parl.gc.ca/InfoComDoc/36/1/HEAL/Meetings/Evidence/hcalev67-e.htm>

⁵²⁵ The combination of witnesses at this session was no coincidence. In addition to explicitly asking for Dr. Nelson, the 'brain death' expert to testify, the Rabbi and other pro-transplant ethicists were intentionally scheduled to present alongside the dissenters in order to counter their claims. (personal communication, Reform Party employee of a Member of Parliament). Selection of witnesses is part of the party politics that occur at the standing committee level.

⁵²⁶ No. 67 (0910, 0915) Rabbi Reuven Bulka, Individual Presentation

⁵²⁷ *Ibid.*

facilitate public commitment to cadaveric organ donation known as ‘mandated choice’”⁵²⁸ To justify the need for organs, Dr. Spital showed statistics of the progressive rise in the waiting list in the United States while the rate of transplants remains relatively constant. The tragedy, he testified, is that “this morbidity and mortality is preventable, since we are recovering organs from at most about half of potential donors. So every day, life-saving cadveric organs are continuously being lost.” To overcome a barrier that accounts for the low rate of procurement, he argued that family consent to donation should be eliminated altogether. Dr. Spital justified the “slightly coercive” nature of forcing all citizens to decide on posthumous organ donation prospectively on the grounds that “minor burdens” are tolerable “when the benefit to be procured...is great.” In addition to acting as an educational tool, Spital added that removing the need to obtain family consent would “eliminate delays...which can jeopardize the quality of organs.”⁵²⁹

Following Dr. Spital, Dr. John Woo-Sup Yun opened his remarks by stating that he may be the only dissenter “in the whole enthusiasm for transplant.”⁵³⁰ Stating his position as one of ambivalence and objection, the basis of his argument was philosophical. By describing the actions of physicians “bridging” patients from person to object, treated for their organs, he exposed the distinction between ‘brain dead’ and dead. Upon analyzing the medical intervention of organ removal, he came to reject the existence of a category of ‘non-person’ in-between alive and dead. In his view the ‘brain dead’ are alive and are persons.

Dr. Yun recounted a personal voyage of transition from a supporter of organ harvesting to an objector. This reversal happened as a result of a friend’s challenge of what he took for granted as well as observation of a different reality thinking about medical intervention in the dying and when death occurs in the context of another kind of clinical practice. Dr. Yun stated that although he counsels people about life and death issues, as an oncologist who treats patients slowly dying of cancer, “many of my patients teach me their meaning of death.” By listening to patients and their families, he learned that people had meanings of death different from his own. Dr. Yun told the Committee

⁵²⁸ No. 67 (0920) Dr. Aaron Spital, Associate Professor of Medicine, University of Rochester and Nephrology Unit

⁵²⁹ *Ibid.*

⁵³⁰ No. 67 (0925) Dr. John Woo-Sup Yun, Individual Presentation

that although Caucasian, Chinese, East Indian, Christians, Buddhists, Sikhs all share a common value that life is precious and worth preserving, they do not share one view of when life ends. His example was Buddhists who believe that death occurs only once the spirit leaves the body after all signs of life - heartbeat, breathing, or movement - are no longer apparent. He has therefore been asked to leave the body in the same position, same room, same clothes, for hours "after apparent death." It is not appropriate for medical professionals to be present once the end of life takes hold. This experience illustrates that unique views rather than uniformity prevails in the meanings people attribute to death. For this reason, Dr. Yun asked the committee to respect difference and be cognizant that "many cultures object vigorously...to the mutilation of the body."⁵³¹ He cautioned that "the western scientifically and technologically driven culture should not think itself superior to these cultures."⁵³²

As an intern in a busy trauma hospital a decade ago, Dr. Yun told the Committee that he "had the opportunity to *keep alive* brain-dead patients for organ transplant."⁵³³ Given that "there was no objective difference before or after the patient was declared brain-dead by a neurologist or myself," what is officially called "donor management," in his view could be considered "life management."⁵³⁴ Dr. Yun stated:

At that time, there was always an aspect of excitement in adjusting the ventilation support machines, or so-called life support machines, and in making sure the urine output was maintained to perfuse kidneys with powerful drugs and fluid. One had to monitor carefully the electrolytes in varying aspects of the body to *keep the donor alive*, or else the whole thing would become futile. So-called brain-dead patients needed all the skills of intensive care to keep them alive.⁵³⁵

Now practicing a entirely different type of medicine, this doctor only recently began to re-examine the whole question of organ transplantation. He admitted that the arguments in favour of transplantation sound very life-giving and the thought of giving part of oneself so that someone else can go on living is appealing.

⁵³¹ No. 67 (0930) Dr. John Woo-Sup Yun

⁵³² *Ibid.*

⁵³³ *Ibid.* (emphasis added)

⁵³⁴ *Ibid.*

⁵³⁵ *Ibid.* (emphasis added)

The problem started, however, when I began to think about the life of the donor. I assumed that the donor was dead. Once dead, no one will object to any way we dispose of the body, as long as it is respectful. But now I believe those patients I looked after as an intern in ICU were alive.⁵³⁶

Dr. Yun stated: "When I scrutinized my own assumptions and the definitions I took for granted. [And] once I accepted that brain death was not death, the whole process was brought into doubt."⁵³⁷ Looking upon his actions as an intern from a philosophical rather than biological point of view, Dr. Yun faced questions that lay outside the domain of medicine. As the U.S. President's Commission had done, this doctor asked himself whether a 'brain dead' patient could be considered dead. His analysis was based on observation of death as a process,

Often when we withdraw the life support machine and IV medication, death will ensue, and follow quickly. But that's my whole point; only when we stop life support measures does death ensue. But is there more than one death—brain death and real death?

Thinking more carefully about the inconsistency involved led him to recognize 'brain death' as a category distinct from death. Dr. Yun's answer, based on adherence to the view that there can only be two states—alive or dead—was that death is not 'brain death' but "natural death," when life support is removed and "the body follows its natural course."⁵³⁸ He offered to the Committee the questions appropriate to this issue that he was then forced to confront:

Is brain-dead the same as dead? I answer "no".

Is imminently dying the same as dead? I answer "no".

Would the consent of the dying patient make the ending of life justifiable? I answer "no", as I do in the case of euthanasia.

Such considerations lead to further questions of the appropriate role of medical intervention relative to what is considered "natural" and causing harm.

...There is an objective difference between the death that follows stopping life-support measures and the death caused by removing a heart or lung. Yes, even if

⁵³⁶No. 67 (0925) Dr. John Woo-Sup Yun

⁵³⁷No. 67 (0930) Dr. John Woo-Sup Yun

⁵³⁸*Ibid.*

we obtain full consent prior to the patient becoming unconscious, even if we get the family on side, the difference is that in the former case, stopping life support, the body follows its natural course. In the latter, removing a heart or lung, we directly intervene.

Likewise, there's a difference between someone dying from a car accident and dying due to the removal of a heart or lung. The latter action requires direct intervention.⁵³⁹

His concern that organ removal could act as an operative cause of death echoed the claim made in the 1976 case of *R. vs. Kitching*. As described in chapter three, the judge in that case decided that what mattered was that the patient "could not have lasted." To the contrary, Dr. Yun's view is that the patient is still a person regardless of an "imminently dying" prognosis.⁵⁴⁰

Having stepped outside the truth of the transplant episteme and opened up the 'black box' of 'brain death', Dr. Yun said, "Now I realize that 'brain dead' is a diagnosis instituted under certain criteria with organ donation in mind."⁵⁴¹ As such, Dr. Yun suggested to the Committee the idea put forward by Ian Hacking that 'brain dead' patients "came into being at the same time as the kind itself was invented."⁵⁴² Moreover, the acceptance of 'brain death' "changes the space of possibilities for personhood."⁵⁴³ Dr. Yun's testimony offers a counter truth: that persons do exist beyond the pronouncement of 'brain death.' This means that these dying patients are not legitimate objects of medical intervention *for someone else*. To intervene other than to save their life is a violation. Dr. Yun asked the Committee whether using persons as natural resources is morally right.

Consider the term 'organ harvesting'. What does this metaphor imply, that the donor's body is some kind of plant from which fruit - human organs - can be obtained?

I believe using another person as a means, even for a good cause, is wrong. We have to treat *persons* as ends in themselves. Donors cannot be thought of as a means for organ transplant.⁵⁴⁴

⁵³⁹ *Ibid.*

⁵⁴⁰ *R. vs. Kitching* [Man.] [1976] 6 W.W.R. 697, 32 C.C.C. (2d) 159 (Man. C.A.) p. 715. See chapter 3.

⁵⁴¹ No. 67 (0930) Dr. John Woo-Sup Yun

⁵⁴² Ian Hacking, 1986. *op.cit.* p. 228.

⁵⁴³ *Ibid.* p. 229.

⁵⁴⁴ No. 67 (0930) Dr. John Woo-Sup Yun (emphasis added)

To examine what is implied in the diagnosis, he reversed the question:

When all the functions of the brain cease, is one less alive? How about when the brain only partially functions? Is one less alive?

Concluding his testimony Dr. Yun urged legislators to “resist all temptation to liberalize the definition, legal and otherwise, in terms of the availability of organs. A person is either dead or alive, and many people have different meanings for that. Please respect that.”⁵⁴⁵

The last speaker of this panel to testify, Dr. John Dosseter followed Dr. Yun in resuming the discourse of donation. Introduced by the Chair with a friendly remark on his wisdom, Dr. Dosseter proceeded to give a first hand account of how he and other transplant surgeons stopped looking for organs from the 90% of patients who die of cardiac and respiratory function once it became acceptable to remove organs from patients declared ‘brain dead’ with the heart still beating.⁵⁴⁶ To now meet the current demand for organs, he argued in favour of using organ-first deaths from ‘non-heartbeating cadaver donors’ as a source. Dosseter stated that in some European countries over half of all donors are from the non-heartbeating cadaver donor group. As surgeons at Dr. Barnard’s conference in 1968 discussed, when the “traditional” criteria for death (cessation of breathing and heartbeat) are used for the diagnosis of death, kidneys can be removed and function recovered within “periods of up to an hour and a half of delay” between declaration of death and removal.⁵⁴⁷ In Dosseter’s view, the severity of the organ shortage justified expanding the donor pool by changing protocols determining which patients are classified as ‘potential donors’.

⁵⁴⁵ *Ibid.*

⁵⁴⁶ No. 67 (0935, 0940) Dr. John Beamish Dosseter, Individual Presentation

⁵⁴⁷ *Ibid.* See chapter three.

5.2.1 *Response to Dr. Yun: Unwilling to Engage*

During the question and answer period that followed, the first five of eleven legislators who queried the panel of witnesses asked questions in response to Dr. Yun's testimony. Aside from Mr. Keith Martin, who sought to deconstruct this counter truth by drawing the focus back to the recipient, the four others used different approaches to digest what was a disruption to the legitimate considerations of the transplant episteme. One sought to verify that a technical absolute for 'brain death' existed; another sought to better understand his point of view; and, a third tried to incorporate an aspect of Dr. Yun's testimony into the "real" policy questions being considered.

The first question of the session was made by Mr. Keith Martin, a Reform Party Member of Parliament, physician and public advocate of organ donation, who introduced the 1997 organ supply motion to the House of Commons.⁵⁴⁸ Articulating precisely the bias that Dr. Yun and the two other dissenters warn of influencing when the brain damaged patient is given up on, Mr. Martin responded to Dr. Yun's testimony by asking Dr. Spital or Dr. Dossetor to explain to the Committee:

Mr. Keith Martin:...what it would be like to harvest an organ after the so-called life support system was turned off, whether those organs would be viable or not, and whether in transplant surgery you would have a much greater chance of having a viable organ transplanted if that organ was removed from somebody on cardiopulmonary support as opposed to turning the cardiopulmonary support off, letting that person so-called die, and then having to engage in the extraction of that organ and the transplant of that organ.

Perhaps you could tell the committee about the viability of that organ being transplanted into somebody who simply does not have an option in terms of receiving that organ, who needs it to live.

It is the quality of the organ to the life of the chimera/recipient that matters, not whether the first patient still is alive or not. In making this statement, the legislator clearly disagreed with Dr. Yun's assertion that such patients still need *their* organs because they are still using them to live. In the conflict over organs needed to sustain the lives of two patients, the moral imperative to save the life of potential recipients trumps waiting for the "so-called" death of the original owner. Dr. Spital responded:

⁵⁴⁸ Notice of Motion, M-222, Journals No. 014, House of Commons of Canada, 36th Parliament, 1st Session.

Dr. Aaron Spital:...if we were to remove organs simply because they worked better, without paying attention to the ethical concerns, from an ethical point of view I think that would be indefensible.

So for me, the issue is not that, yes, the organs are of better quality—from a heartbeating preparation, yes, there's no doubt about that—but whether we are ethically justified in removing the organs from a cadaver where the heart is still beating.⁵⁴⁹

Not receiving the answer he was looking for, Mr. Martin's attempt to dismiss Dr. Yun's argument by justifying organ removal on the grounds that another patient's life is at stake failed. His perspective reflects precisely the view of Dr. Cooley, the U.S. transplant surgeon who reminded participants of Dr. Barnard's conference in 1968 that it was the recipient who must be uppermost in the doctor's mind. He argued:

In my opinion the clinician can become too pre-occupied with the rights of the dead, namely the donor, at the expense of the recipient. We should not jeopardize the possible survival of the recipient while we are waiting around to make a decision whether the cadaver, as you call it, is dead or not.⁵⁵⁰

Without even mentioning 'brain death', personhood status of the first patient, dying brain-first, appears to be irrelevant to Mr. Martin who is a legislator and practicing physician.

Next, the Member from Drummond, Ms. Pauline Picard, stated that she found Dr. Yun's presentation "rather disturbing." Qualifying her ability to comprehend, "since I am not a scientist myself," she asked Dr. Dosseter who "is a master in this field" to clarify the difference between 'brain death' and death.⁵⁵¹ He replied: "One has to experience what brain death actually means before one can convince oneself that the individual is dead, though their heart is beating. This is a difficult concept to get across to people, and I understand Dr. Yun's point." Giving an account that Scheper-Hughes and Lock would call "radically materialist thinking,"⁵⁵² the doctor offered a story to convince the group of this 'fact':

⁵⁴⁹ No. 67 (0955) Dr. John Beamish Dosseter

⁵⁵⁰ From Shapiro, Hillel. 1968. quoted in Margaret Lock 1996. *op.cit.* p. 582.

⁵⁵¹ No. 67 (0950) Dr. John Beamish Dosseter

⁵⁵² Nancy Scheper-Hughes and Margaret M. Lock "The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology" *Medical Anthropology Quarterly* 1:6-41, 1987. p. 8.

Dr. John Dossetor: At the risk of being a little macabre, I will describe a case, reported in the *British Medical Journal*, of a young woman who had a severe cerebral hemorrhage while pregnant. She became brain-dead, brain-dead by the fact that her brain had no electrical activity. She was kept alive, if you want to call it that, though I personally call it ‘body on life support’—or rather, ‘organ support’—for a matter of 10 weeks, I think, before she was delivered of a live infant.

There have been a number of such cases. It was not possible to maintain the respiration and cardiac vasomotor tone and other aspects after delivery, and she went to a delayed autopsy, delayed by 10 weeks.

The reason for using that type of language is that when the autopsy was carried out, and the skull was opened, there was nothing but water inside. The pathologist describes how he was able to look down into the upper part of the spinal canal, because there was nothing there.

It is possible for a brain to not only die but also undergo what's called “liquidive necrosis”—that is, it becomes water—and yet maintain the rest of that preparation in a state of physiological function. I'm trying not to use the word “live”, because the body is not alive.

These are very difficult concepts. I've taken an extreme example, which I hope doesn't sound too shocking, but I think it is a fact that there are reliable ways.⁵⁵³

Proof of ‘brain death’ for Dr. Dosseter is thus the absence of electrical activity and solidity of the brain. It is the point at which the brain began to disintegrate, not when this is observed that is taken as the moment of death. Although Dr. Dosseter claimed that “It's on this type of evidence that people are convinced that the brain is dead,” immediately thereafter he conceded: “now, whether the brain is dead means that the person is dead, as I believe, is a matter of some degree of philosophical and religious judgment.”⁵⁵⁴ With this comment he sought support from another authority by motioning to the rabbi present. “I'm glad Rabbi Bulka has been so strong in pointing out that all the major religions believe one can reliably diagnose that a brain is dead, and when that is the case that the individual has already died.”⁵⁵⁵ Before the Rabbi could speak Dr. Yun interjected to immediately disagree: “I think that kind of example is precisely the kind of example we would use to argue that brain-dead is not necessarily dead. Let's raise hands,

⁵⁵³ No. 67 (0955) Dr. John Beamish Dosseter

⁵⁵⁴ *Ibid.*

⁵⁵⁵ *Ibid.*

shall we, on who believes that someone who can carry a baby for x number of months is dead?”

After a moment, the Chair moved on to the next legislator, the Member for Beaches—East York, who sought to understand Dr. Yun’s testimony by asking him to explain death on technical grounds.

Ms. Maria Minna: In your presentation, you said that “often” when we withdraw life support machines and IV, death follows, but you don’t say “always”, which is interesting. Are you suggesting that death, as you call real death of the body, does not always ensue? What does that mean in terms of having diagnosed brain death, and what is the criteria of brain death? I know I heard it means there is no electrical activity. I guess you’re relying on what, sophisticated...?

Dr. Yun responded by recounting a recent ICU call where he was asked to pronounce someone brain dead. Describing the ‘death tests’ stipulated in a hospital protocol he is instructed to rely upon, he noted that it did not include the absence of electrical activity. The Chair reminded the Committee members that someone in the next panel, specifically contacted for this purpose, would give a presentation on all the protocols associated with brain death. Nonetheless, Dr. Spital interjected to tell the Committee that although he does not pronounce brain death routinely, “It is my understanding that the criteria are much more stringent than what was just outlined here” and that “the criteria for the pronouncement of brain death are extremely reliable.” Specifically in response to the tests Dr. Yun had described, he said:

Dr. Aaron Spital: For example, some of those things that were outlined can happen in comatose people who have potential for complete recovery. There needs to be more than that. In brain death there is no circulation to the brain. There is no blood flow to the brain. There is no electrical activity. There also has to be the absence of reversible factors, such as drug intoxications and hypothermia.⁵⁵⁶

As additional proof, he added the prognosis of cessation and judgement of ‘cyborg status’ as other signs that indicated ‘non-personhood’:

Dr. Aaron Spital: It should be stated that all of those persons declared brain-dead by somebody who really knows the criteria will, when life support is withdrawn,

⁵⁵⁶ No. 67 (1000) Dr. Aaron Spital, Associate Professor of Medicine, University of Rochester and Nephrology Unit

have cessation of cardiac and pulmonary function very quickly. They are dependent on life support, absolutely dependent on it.⁵⁵⁷

At Dr. Yun's next opportunity to speak, he clarified that an angiogram or EEG to measure blood flow or electrical activity were not required, only a clinical process for checking the brain stem. Regardless, in his view biological tests were insufficient to declare the patient a 'non-person'. Dr. Yun told the Committee that even in passing the tests in the protocol, he found himself "in a bit of a dilemma as to whether I should declare the person brain-dead."

Dr. John Yun: What I actually did showed that all evidence of brain-stem reflex was absent. It met the criteria for brain-dead, but was the person dead?

That's the theme that keeps coming back for me. If the person is alive, I think the question takes on a totally different tone.

So my change of thought is very simple in terms of the idea of when this person dies. Does a person die more than once, brain death and then later a real death? Is the seat of the soul in the brain?

It's that kind of question that my change in perception came from.⁵⁵⁸

While offering medical observations on the process of death, Dr. Yun insisted the appropriate questions that ought to be brought to bear on declaring the end of personhood were not technical but philosophical. Indications of death, as what signals the end of the person, thus arise from the fundamental consideration the soul in relation to the body – in other words, the embodiment of personhood. Dr. Yun decided that he does not think someone is dead "just if that crucial organ is no longer functioning at all." It was only upon deciding the point at which the soul, as the essence of the person, departs—after all apparent signs are gone or at some earlier point—that the question of when death ensues can be answered. Thus, religion and culture have the most to contribute to the question of the end of life, not medicine.

At his next turn to speak, the rabbi chose to reply to Ms. Minna's question:

Rabbi Reuven Bulka: I would like to add to this. This issue, the question of whether brain death is an acceptable criteria, has been a subject of intense debate in Jewish medical ethics areas.

⁵⁵⁷ *Ibid.*

⁵⁵⁸ No. 67 (1010) Dr. John Woo-Sup Yun

In the original Talmudic sources about it, the criteria for death was basically cessation of breathing. The general conclusion that has been reached, and the consensus more or less accepted by the majority, is that cessation of brain activity, measured in the ways Dr. Spital has outlined, is effectively the equivalent of decapitation. That's the metaphor used. Basically, if the head and the body are not interacting, it's as if the head has been cut off from the rest of the body. It's just that you don't see it. It's effectively the same thing.

The general presumption is that if a person is decapitated, they are dead, and this would be a case of decapitation without the head being decapitated.

As the sole representative of religious authority to provide testimony at the hearings, Rabbi Bulka's contribution to the debate illustrates the deference to and dependence of religion on medical authority. Jewish leaders were not in a position to dictate, only to respond to medicine. No longer the overseers of death, the dominant group in this religion adjusted which signs were indications of death to come into alignment with the dominant medical view. Based on Rabbi Bulka's explanation, this decision was arrived at for Jews by asking the question of what the cessation of brain activity meant. Interpreting it as a lack of interaction between the head and the body, this was judged to be equivalent to decapitation, not paralysis or a 'locked-in state'.⁵⁵⁹ Considering decapitation death, it is presumably acceptable to resuscitate, remove and reuse the organs from a decapitated body.

Shifting attention away from how to service organ-dying patients to concerns regarding the donor was difficult. The Member from Nanaimo—Cowichan and Member from Lambton—Kent—Middlesex responded to Dr. Yun's testimony by attempting to reconcile it with the 'legitimate' concerns of the discourse of donation: how to increase the supply of organs.⁵⁶⁰ In response, Dr. Yun warned of the implications of a bias in favour of the recipient:

Dr. John Yun: The only reason we think about mandated choice is that there is a lack of organs, so be careful with your intentions.

Much of the data is presented—you have seen the graphs—with organ donation in mind, self-interest, in a way. And that's not in a negative way; everybody who is

⁵⁵⁹ See below, page 160 and 163.

⁵⁶⁰ Mr. Reed Elley (Nanaimo-Cowichan) asked how difference could be accommodated in public policy formation with respect to mandated choice as a means to improve the harvesting system. Ms. Rose-Marie Ur asked him to explain what changed his mind and whether he was in favour of xenotransplantation. Time did not permit a response to the second question.

involved with this has great compassion and the noble ideal of saving lives, but I think we have to look at it very carefully in terms of the life of a donor.

...We all have pure intentions, but when it comes to practice, the assumptions we have, the biases we have, will affect the purity of our intentions.

I'm not going to admit that if someone is all shrivelled up and dying I don't think of them as a person, but it is very tempting to just walk away and not give the 100% that is due a person.⁵⁶¹

The influence of the 'double gaze' viewing the patient as subject and object was a concern raised by Dr. Starlz thirty years earlier when he stated that:

...the new risk is introduced that the terminal care of such potential donors may be adversely influenced by the events which are expected to follow after death, which might conceivably remove whatever small chance there might have been for survival.⁵⁶²

The next two legislators ignored Dr. Yun to continue consideration of how to improve the procurement system by asking Dr. Spital, Rabbi Bulka and Dr. Dosseter about mandating all Canadians to decide on donation and the rights of families versus individuals in granting consent to donate. Ms. Judy Wasylycia-Leis, the Member for Winnipeg North Centre, stated that the rights of the family to veto individual consent had "proven to be one of the most divisive issues before us."⁵⁶³ Indeed, by not engaging the matter, the Committee did not divide on the question of whether the donor is truly dead or remains a live person.

This session nonetheless ended by returning to the determination of personhood with respect to the question of using anencephalic newborns as donors. Although Rabbi Bulka did not appear informed enough to take a clear position, he and Dr. Spital stated that families should be allowed to decide whether to offer the organs of this type of baby for donation. Dr. Yun once again spoke against the majority by pointing out the premise of the argument for considering this category of the dying: that only those with full brain function are owed the obligations of personhood.

⁵⁶¹ No. 67 (1015) Dr. . John Woo-Sup Yun

⁵⁶² Joseph E. Murray, "Organ Transplantation: The Practical Possibilities," Wolstenholme and O'Connor, 1968 *op.cit.* p. 67. (emphasis added) In his autobiography, Dr. Starlz wrote that he later reversed his view once safeguard protocols were introduced.

⁵⁶³ No. 67 (1015) Ms. Judy Wasylycia-Leis, Member of Parliament for Winnipeg North Centre

Dr. John Yun: I strongly disagree with the previous two speakers. Many anencephalic babies do breathe spontaneously. They do swallow. They do react to stimuli. They are not brain-dead, as I have been taught, with entire brain-stem reflexes, etc.

I'm not trying to be personal—I'm sorry—but we already have assumed that an anencephalic baby, without a brain, is not a person. To me, that's wrong.

Either someone is living...and if someone is alive, because they have no brain they're not necessarily not a person. The seat of the soul, the Christian point of view, is not necessarily the brain. Be very careful about that. Someone is either alive or dead. If someone is alive, they and their family deserve the entire protection of the law.

So be very cautious about proceeding with the assumptions you make.⁵⁶⁴

He rejected expanding the pool of potential donors by including this group of dying patients in the category of 'non-persons'. However, in this case, Dr. Dosseter also answered in the negative. He stated that although they always die, anencephalic babies do breathe and therefore have brain-stem function. For him this meant that "whether they have brain death or a failure of brain life is a philosophical point." Upon hearing this, the rabbi partially revoked his position by admitting that he presumed such babies had no brain activity. When Mr. Ovid Jackson, the Member from Bruce-Grey, asked how long an anencephalic or brain-dead child lives, Dr. Yun attempted again to engage the Committee in the fundamental question of the temporal boundaries of personhood. He sought to distinguish a dying patient from a dead patient by arguing that "many of my cancer patients do die in a few days, too, but the fundamental question is not how long they live but whether they are a living person."⁵⁶⁵ The legislator replied: "For me, that's an educational point." Resuming talk of 'real' issues, this session concluded with Dr. Dosseter stating, in reference to organs, that the only problem in transplantation is "the failure to supply."⁵⁶⁶

⁵⁶⁴ No. 67 (1030) Dr. . John Woo-Sup Yun

⁵⁶⁵ No. 67 (1035) Dr. . John Woo-Sup Yun

⁵⁶⁶ No. 67 (1035) Dr. John Beamish Dosseter

5.3 Dr. Oliver: Living Proof that the Brain Dead Survive

Following a short recess, a second set of witnesses testified. The first and last of five witnesses to testify, Dr. Ruth Oliver and Dr. Micheal Brear followed Dr. Yun's dissent from the transplant episteme by challenging 'brain death' but offered other reasons to question this category. These doctors did not challenge the legitimate scope of the medical domain. Instead, their criticisms called into question the validity of criteria used to diagnose 'brain death'. Dr. Oliver's story exposed the conditions of medical practice in trauma situations to confront the idea that patients can be standardized and medical literature relied upon as a source of absolute knowledge of what is and is not possible. Dr. Brear attacked the authority of the diagnosis on scientific grounds. By presenting studies undermining the truth claim that 'brain death' is a fact and is death, he suggested that medical literature is not objective, comprehensive or apolitical. Also speaking were Dr. Francis Rolleston, Director of Ethics and International Relations at the Medical Research Council, Dr. Eike-Henner Kluge, Chair of the Department of Philosophy at the University of Victoria, and, the 'expert' on 'brain death' contacted by the Committee, Dr. Robert Nelson, Professor of medicine in neurology, from the Ottawa Hospital.

Dr. Oliver began by telling the Committee that she was living proof that brain-death is not death. Aware of the radicalness of her claim she stated that,

Dr. Ruth Oliver : The most important thing I can offer you today is that if you can see me, hear me, and understand what I am saying, whether or not you believe what I say or agree with what I say, you need to know that I, 22 years ago this month, survived the criteria for clinical death—some might say brain death. Within a period of less than 24 hours, I was there at least two times, and had to be resuscitated three times.

Now, 22 years later, I'm living testimony that people survive so-called clinical death and brain death, and not just survive as vegetables—a derogatory term—but can become totally functional, totally contributing members of society.

...So remember, you've seen one and heard one. You know they can survive. That's the most important message.⁵⁶⁷

⁵⁶⁷ No. 67 (1050-1055) Dr. Ruth Oliver, Individual Presentation.

She then described in detail the intensity of her ordeal as a patient slipping in and out of life/death based on the medical records she obtained from the Kingston General Hospital where this event took place in 1977. Her testimony was the first and only insight the Committee heard in the fourteen days of hearings into what occurs in intensive care when physicians struggle to save someone's life. A thirty year old woman, Dr. Oliver was admitted to the hospital 35 weeks pregnant and experiencing heart palpitations. Diagnosed as having hydramnios (explained as a great deal of fluid), labour was induced and she gave birth to her stillborn, anencephalic son. Complications continued to escalate after this point.

My first resuscitation involved giving me blood, because at 3 a.m. the following day, March 27, about 26 hours after the delivery, I was bleeding continuously. I deteriorated into a loss of consciousness and was comatose by 8 a.m., with a very stiff neck. Blood pressure was down to 70 systolic.

So that was my first resuscitation. I needed a lot of blood transfused.

At that point they didn't know why I was unconscious. Carotid angiograms were done. They found that the blood vessels were deviated, so they thought I had a hematoma, or a brain bleed, if you like.

A neurosurgeon was called in. They did a craniotomy and found there was nothing wrong with my brain. There had been no bleeding. There was no problem when he opened, but right after he opened, the brain began to swell rapidly and then bleed from every level they had made the incision through. It became uncontrollable.

At this point I went into a coma, and stopped breathing. They put me on a respirator. I had poor eye movement and no response to very deep pain, so I was returned to the ICU in critical condition, because I was continuing to ooze.

One hour after the surgery and right in the ICU, I developed the irreversible symptoms of dying—fixed, and dilated pupils, quadriplegia, and no response to pain. Fortunately for me, my neurosurgeon right there in the ICU opened the flap, put in a syringe, and pulled out a collection of blood. Immediately my pupils came down and started reacting again, and became equal. They then took me right back to the ICU, because they still had this problem of bleeding.

As they were trying to prepare me for the surgery, I went back into the situation of fixed, dilated pupils, quadriplegia, not responding to pain, and not breathing. That was the third resuscitation.

Again, I had bled a collection of 200 ccs of blood. When you have blood and you have brain swelling, the vital section of the brain that controls your pulse, your blood pressure, slips down into the spinal cord. That is called a tentorial herniation.

As my neurosurgeon later told me, nobody had ever been known to survive a tentorial herniation. I survived it twice. He told me it wasn't in the literature. He'd never seen one, known one, or heard of one.

All of this is to point out that what can look extremely critical, and what seems to be failure at all levels because 24 hours later, I was conscious. The following morning I was intelligent, I was aware, and I was responding to pain. Within 24 hours after that, they took out the respirator.

...After I was conscious enough and aware enough to understand my situation, many people came to see the so-called miracle patient.⁵⁶⁸

Providing the hospital records to the Committee Dr. Oliver concluded her testimony by telling legislators how, after 22 years, the epilepsy she developed as a result of this incident finally subsided this year. She emphasized the intellectual challenges met and her contribution to society thereafter. Only a minor speech impediment kept her from being completely "normal." This dimension of her testimony seemed to imply that her value as a person after having 'brain death' criteria is relevant to this diagnosis, suggesting a judgement of worth is entwined in how the 'brain dead' are viewed.⁵⁶⁹

Dr. Oliver's testimony broke the sterilized portrayal of physician knowledge and ability. The story of her ordeal relayed a case in which doctors were not in control of the situation. They did not know what was wrong and acted upon guesswork. Her life was saved but this was in no way a predictable outcome. Part of her point was to tell the Committee that surprises can happen - patients who could be considered 'potential donors' recover. Medical literature cannot serve or be relied upon to determine every outcome.

Following Dr. Oliver, Dr. Eike-Henner Kluge of the University of Victoria returned the focus of attention to organ-dying potential recipients. In making the claim that those who need organs have a moral right to them, he testified that "a major

⁵⁶⁸ No. 67 (1050-1055) Missing words are due to inaudible recording of the testimony.

⁵⁶⁹ By contrast to my argument in chapter 3 of 'non-personhood', Margaret Lock accounts for this in her contention that what 'brain death' signals is a judgment that "meaningful life" is over. 1996 "Death in Technological Time" *op.cit.*

contributor to the current organ shortage is the transplant societies' refusal to act in accordance with the wishes when next of kin object." Calling this a "ghoul objection," Dr. Kluge argued that allowing the family veto power over the 'brain dead' patient's wishes is illegal, "unethical and uneconomical, and it kills patients on waiting lists."⁵⁷⁰ The evidence he presented found that "one-third to 35% of organs are lost when next of kin are asked despite the fact that there is a valid organ donor card." Since the medical societies that regulate professional conduct of physicians are "circumventing the laws by their protocols" at present, the answer is to cease the violation of informed consent which is a "de facto betrayal of a moral right." He closed with three strong 'truths' of the transplant episteme: "the current organ shortage is unacceptable"; "we are dealing with preventable deaths;" and "Canadians want their wishes to be followed, in this, their final and most meritorious act."⁵⁷¹ His ethical issue to present to the Committee was thus in line with the arguments of American 'experts' on the organ shortage (discussed in chapter four), Jeffrey Prottras and Arthur Caplan.

The next two presentations, by Dr. Nelson and Dr. Rolleston were descriptive. As the person called upon to speak with authority on 'brain death', Dr. Nelson's testimony held the cultural capital of 'expertise'. His status as Professor of Medicine at the Ottawa Hospital gave neurologists the appearance of being neutral, but his testimony confirmed the enrolment of brain specialists in the transplant episteme. He began by describing the 'traditional' criteria and how resuscitative techniques undermined the interpretation of the cessation of heart action or breathing as invariable signs of death.

Dr. Robert F. Nelson : In 1968 a committee met at Harvard and proposed that death could be considered when the brain stopped functioning, and that brain death was equivalent to death of the individual.

Subsequent committees in various jurisdictions all over the world have established specific operational criteria by which a diagnosis of brain death could be determined.

Giving the impression of universality and unproblematic acceptance, he continued:

⁵⁷⁰ No. 67 (1055-1105) Dr. Eike-Henner Kluge

⁵⁷¹ *Ibid.*

In 1987 a group of Canadian neurologists, neurosurgeons and neurophysiologists proposed a set of criteria, adopted by the Canadian Medical Association, that for the past decade have been used throughout this country. In the past month, a special committee of neurologists has published an updated version of the operative criteria.

This conceals the 'double medical gaze' embedded into the criteria for death revealed in the *Donation Services* document which mentioned that the Canadian Congress of Neurology designed the test for apnea to avoid possible deterioration of organs.⁵⁷² Distinguishing the form of legitimation appropriate to this issue, Dr. Nelson stated:

I will not go into the ethical philosophical matters of personhood and what constitutes the essence of an individual. Rather, I wish to focus on biological facts and explain how the average physician goes about trying to determine brain death.⁵⁷³

He then described the parts and functions of the brain and the classifications of 'coma', 'persistent vegetative state' and the 'locked-in state' as conditions which "must be distinguished from brain death."⁵⁷⁴ Rather than outline how 'brain death' is determined, which was discussed in the first session, he addressed "certain caveats people may overlook that are important to consider." Reciting instructions contained in the latest diagnostic guideline, he listed the exceptions to the criterion where a patient may appear dead and yet survive. He spoke on behalf of the profession to say that "in such circumstances we apply additional tests." Regardless, Dr. Nelson stated that "in almost all cases, death is anticipated."⁵⁷⁵

Instead of addressing how it is that Dr. Oliver could have survived, Dr. Nelson chose to take this opportunity to add to the criteria by suggesting six additional safeguards "to make sure that we are not prematurely declaring a person brain-dead."⁵⁷⁶ Rather than be perceived as a weaknesses in the diagnosis and its administration, this move provided the Committee with a means to uphold the legitimacy of the transplant episteme. First, it defined any problem that there may be as one of timing. This subtly

⁵⁷² See chapter four, page 108.

⁵⁷³ No. 67 (1100) Dr. Robert F. Nelson

⁵⁷⁴ No. 67 (1105) Dr. Robert F. Nelson

⁵⁷⁵ *Ibid.*

⁵⁷⁶ *Ibid.*

addressed the crux of the issue - when physicians ought to stop trying to save a patient, - without confronting it. In terminology and substance, the impression given by descriptive accounts of the diagnosis is of physicians waiting to observe rather than prevent the cessation of signs of life, implying that the outcome of death is inevitable. As Dr. Nelson stated, the prognosis of death, brain-first, is what is significant and relied upon. Second, even though Dr. Nelson carefully stated that no problem exists, he offered legislators an action option with which to respond to dissent. Improvements in how the diagnosis is administered reaffirms its status as legitimate by tightening the conditions of its application. Using the 'brain dead' as donors could thereby continue - without confronting the question of personhood or taking seriously the possibility that the diagnosis may be faulty - by once again refining the category and officially tightening controls over its application. Any disquiet caused by Dr. Oliver's story was therefore dismissed as nothing to worry about.

5.4 Dr. Brear: Questioning Authoritative Knowledge

Following the fourth presentation by Dr. Rolleston's on research ethics, Dr. Micheal Brear gave his testimony which spoke against the impression and assertion conveyed by Dr. Nelson and Dr. Spital from the first session, that 'brain death' can be taken for granted as an unproblematic fact. His central argument was that there is not a consensus on 'brain death'. Far from definitive, it is an uncertain diagnosis that is a subject of disagreement within the medical profession. Together, Dr. Oliver and Dr. Brear's testimonies implied that medicine and scientific evidence is not absolute, predictable or infallible.

As a general practitioner, Dr. Brear told the Committee that "much of what I do is to protect my patients from the enthusiasms and fashions of specialists."⁵⁷ His first "important fact" for legislators was to state that "the so-called brain-dead criteria used in Canada do not comply with the legal definition of death." Secondly, Dr. Brear expressed particular objection to the harvesting of organs from "so-called beating-heart cadavers." In his professional opinion, these people who are used as donors,

...are in fact living patients. They are sick, they are dying, but they are living and not dead. Dying is not dead. No matter how rapid the process and how irreversible the process, they are dying, sick people.

There exists those means that shall support their lives. These means are artificial. Their life is real life. These artificial means can only assist a body that is a living body. If the body lives, we live.⁵⁷⁸

Rejecting the separation of personhood from embodiment Dr. Brear's statement echoed Dr. Yun in rejecting the idea of 'brain death'. They saw the same condition as 'body alive' implying personhood. Highlighting the matching of two different orders of death, Dr. Brear raised the issue of the relationship between the two patients that provided an alternate vision of reality and the future.

The second important fact that I wish you to consider is that we're talking about two patients—one with a sick heart and one with a sick brain. We have the means to help one but not the other. What will be the criteria for death when we have treatment for both?⁵⁷⁹

Articulating a more holistic view of the body, Dr. Brear offered a different definition of death similar to Dr. Yun's assertion of 'natural' death:

In the living, the heart, the brain, and the lungs work in unison. Their activity in the living is inseparable. The three separate systems of the lungs, heart and brain are in fact codependent. Death of one system is rapidly followed by death of the other systems. Death involves disintegration, disillusion, and destruction, and I believe a true definition of death should include those codependent three systems—total non-function and the condition of destruction and disintegration.⁵⁸⁰

Based on this concept of the end of personhood, he offered scientific objections to organ removal based on brain-dead criteria. Taking a stance opposite to Dr. Nelson's testimony, which gave the impression of consensus, Dr. Brear argued that the medical literature shows a "...hopeless confusion and division around the world on this issue of brain-dead criteria."⁵⁸¹

⁵⁷⁷ No. 67 (1105) Dr. Brear

⁵⁷⁸ No. 67 (1115-1120) Dr. Brear

⁵⁷⁹ No. 67 (1120) Dr. Brear

⁵⁸⁰ *Ibid.*

⁵⁸¹ No. 67 (1200) Dr. Brear

Dr. Brear stated that a major scientific problem with the 'brain death' diagnosis was that it can only be made at autopsy. This presented a fundamental limitation to its application.

In the biggest study by the National Institute of Health in the U.S.A., as long ago as 1980, known to the medical profession for nearly 20 years, it was impossible to verify that a diagnosis made prior to cardiac arrest in one who is brain-dead by any set of criteria would invariably correlate with a diffusely destroyed brain. How can a condition only determined after death be a requirement for declaring death? Surely this must be the focus of your concentration today.⁵⁸²

Research findings in journals such as the *International Journal of Neurology* indicate that the 'brain dead' are still persons. Evidence for this include finding the persistence of total body function in at least seven cases of brain-dead women who gave birth to healthy babies; the existence of cortical activity in twenty percent of brain-dead people; and oesophageal activity. As well, Dr. Brear told legislators that,

Brain-dead people require general anaesthetic to prevent reaction to pain. The reactions include moving the limbs and trunk. The Lazarus syndrome involves sitting up and crossing the arms over the chest. This reaction to pain also causes marked increases in blood pressure and heart rate, which settle only on giving general anaesthetic.

...Brain-dead people display normal features in developing fevers and bed sores, shivering, and in responding to antibiotics and IV therapy, etc.⁵⁸³

Contrary to the CMA diagnostic criterion of 1974 that state "unusual spontaneous movements of limbs and trunk owing to spinal-cord reflex" are consistent with 'brain death', Dr. Brear rejects the distinction made between bodily movements based on origin that only considers reflexes mediated through the brain significant.⁵⁸⁴ Signs of life from the body rather than the brain demonstrate that people are not dead but alive.

Dr. Brear told legislators that studies show the compensation of live brain tissue taking over the function of absent or destroyed brain tissue. This could account for cases where people have awakened on electrical stimulation, the survival of three children born

⁵⁸² No. 67 (1120) Dr. Brear

⁵⁸³ *Ibid.*

⁵⁸⁴ See chapter three, page 76. Definition of death passed as a resolution at the CMA annual general meeting. *Proceedings of the 107th Annual Meeting Including the Transactions of the General Council*,

with anencephaly and reports of “total recovery from a diagnosis of brain death.” He told the Committee that “A women contacted me three years ago, describing her experience of suffering the locked-in syndrome. Apparently her family were told she was brain-dead.”⁵⁸⁵

Contrary to the knowledge offered by Dr. Nelson, this knowledge of how the brain works indicated that the diagnostic criteria for ‘brain death’ are problematic. Evidence of possible recovery and the inability to affirm the diagnosis prior to autopsy undermine it as a means of declaring the end of personhood. Contained in the 1974 criteria for ‘brain death’, but dropped thereafter, was the stipulation that the absence of signs of life must be deemed “irreparable with the presently available means.”⁵⁸⁶ Dr. Brear made the case that, “in view of the sheer weight of this scientific evidence, many doctors are rationalizing...in their writings and in conversations.”⁵⁸⁷

Intimating representation of at least some of his colleagues, Dr. Brear told legislators that medical staff were uncomfortable with the practices required of them by this *technology of health*. With respect to organ retrieval, he asked a young physician “whether what he was doing was right or wrong. His answer was, ‘Wrong’.” In another instance, when asked to verify brain death, another young doctor, who “knows the falsity of brain-death criteria,” phoned him in the night seeking advice. Dr. Brear argued that these cases illustrate that new mandates in hospitals forcing doctors to discuss organ donation with relatives are “an impossible heavy burden on doctors.”

Finally, Dr. Brear concluded by quoting from medical literature. He recited a passage from an article by Professor Dr. Truog, an anaesthesiologist at Harvard - where the criteria for brain death were established 20 years ago.

‘The diagnosis of brain-death is incoherent in theory and confused in practice. However, there is precedent for justified killing. The idea is not anathema to the public. Surveys show that one third of physicians do not believe brain-dead patients are really dead...but justify their actions.’

Toronto, June 24 - 26, 1974. *op.cit.* See chapter 3.

⁵⁸⁵ No. 67 (1125) Dr. Brear

⁵⁸⁶ *Proceedings of the 107th Annual Meeting Including the Transactions of the General Council. op.cit.*

⁵⁸⁷ No. 67 (1125) Dr. Brear

...believes the deception of brain death has well served its purpose in preparing the public to tolerate the practice of harvesting of organs from the living.⁵⁸⁸

Dr. Brear was adamant that, "there has been evidence of the crumbling consensus of opinion on brain death" across the world in the last year or so. A Dr. Tontifilippini of Australia "wrote just a few months ago that, 'to say that the brain-dead are dead is clearly a falsehood'."⁵⁸⁹

At this point, the Chair of the Committee cut off Dr. Brear's presentation by asking the only question directed at the two dissenters in the discussion period that followed. He inquired that, if, as suggested in his testimony, "there is a practice amongst physicians to accelerate, if not in fact induce, death" which would be against the basic tenet of medical society to do no harm, would someone bring this to the attention of the college of physicians and surgeons? Dr. Brear replied that he did not know.

The Chair (Mr. Joseph Volpe (Eglinton—Lawrence)): Would it be a logical thing to ask any practitioner of medicine today why they would not have raised this with their own college?

Dr. Michael Brear: I have submitted an article on this to the Canadian Medical Journal, upon which this presentation is based. It was dismissed by the editor as uninteresting to the reader and too long, and easily done by a letter to the editor.

I think there's a certain attitude and a certain ideological belief in the establishment in medicine today. Yes, I think there's a certain view, and I believe certain views are not acceptable.⁵⁹⁰

Dr. Brear's response that an orthodoxy exists within the profession was left hanging. It could have been followed by a recognition that the form of legitimacy of medical science permits only questions of accuracy even though diagnoses emerge and fade away over time. Moreover, for this reason public forums occasionally serve as sites for disputation over the appropriate application and legitimacy of diagnosis, as was the case in the 1987 'Cleveland affair' over child sexual abuse in Britain.⁵⁹¹ This knowledge might have altered Mr. Volpe's assumption that a process for disagreeing with diagnoses exists

⁵⁸⁸ *Ibid.*

⁵⁸⁹ No. 67 (1125) Dr. Brear

⁵⁹⁰ No. 67 (1130) Dr. Brear

⁵⁹¹ See Collins, Kendall and Michael, 1998. *op.cit.*

within the regulatory bodies of the medical profession, and his reliance upon this as justification for not taking the dissenters' testimony seriously.

5.4.1 Marginalization and the Presence of 'Experts'

Dr. Oliver and Dr. Brears' testimonies were almost entirely ignored. Although two Members of Parliament stated that these presentations were "interesting" and another said that he was "jolted" by some of the information Dr. Brear presented, only one question was directed towards these dissenters. Of the seven legislators present, only two legislators posed questions regarding 'brain death' but directed their questions to Dr. Nelson. The others chose to ask Dr. Kluge about his ideas for increasing the donor rate.

At her turn to ask questions, the Member for Beaches—East York, Ms. Maria Minna, continued to seek assurance that 'brain death' is a fact by directing question to the 'expert,' Dr. Nelson. Her focus was on the criteria used and how it is applied, specifically whether the electrical brain test was required or not, whether there is there a margin of error and, "whether there was a consistency in the medical field in deciding whether or not a person is brain-dead...paramount to saying...that the person is dead or not."⁵⁹² Dr. Nelson replied:

Dr. Robert Nelson: The criteria have been accepted by the Canadian Medical Association and are generally the same across the country. I should just emphasize, though—perhaps I didn't make it entirely clear—that generally the criteria indicate that one can make a diagnosis by bedside examination.

When there is some question about it, then we do other tests, such as an electroencephalogram, but in many cases this may not be mandatory or necessary.

The MP's second question sought clarification of Dr. Nelson's mention that when in doubt doctors wait a few days to see whether the diagnosis of brain-death is correct.

Dr. Robert Nelson: What I was trying to emphasize with the time is that if one finds that almost all the criteria are there but you're not quite sure about whether or not the patient, for example, is able to breathe when you turn off the respirator, if there is some detail that doesn't meet all the criteria, then we usually do not say that the patient is brain-dead at that point. We examine the patient after a period of time has passed to make sure that all the criteria are met before we actually do say that the patient is brain-dead.

⁵⁹² No. 67 (1145) Ms. Maria Minna, Member of Parliament for Beaches—East York

In this exchange, the legislator is trying to find absolute assurance but the 'expert' physician can say no more than "generally," "usually" and "if" not all criteria are present they will wait for them to appear. In Dr. Oliver's case where some criteria were present, the attending doctors did not wait but continued to treat her and saved her life. Dr. Nelson does not mention that possibility. The impression he gives is that the presence of the criteria indicate that it is only a matter of time before they are all present. Dr. Kluge added:

Dr. Eike-Henner Kluge: Some presenters may be under the impression that brain death is not legal in Canada. I would remind this committee that it was established in 1976, in the Manitoba Court of Appeal, in a case called *Regina v. Kitching and Adams*.

In fact, that is the basis on which the Canadian Medical Protective Association recommended to the Canadian Medical Association that in fact they come up with the criteria Dr. Nelson has talked about.

Again, to clarify something, if I may, there are two different concepts of brain death floating around. One is what is called a "whole" brain death, while the other one is purely "cerebral" death. Whole brain death includes the definition included in the legal case of *Regina v. Kitching and Adams*, which includes the brain stem. There is no known record of anyone surviving that at all, ever.

Ms. Minna's third question: "is research done in all medical spheres. How much research is going on in the field with respect to brain activity?" did not receive a reply.⁵⁹³

At her turn, the Member for Lambton—Kent—Middlesex, Mrs. Rose-Marie Ur, also directed a question to Dr. Nelson, "regarding ethical concerns."

Mrs. Rose-Marie Ur: Do you not think the ethical concerns in transplantation can probably be addressed by, if we have the qualified people, whether it be the acute care team as well as the procurement team, setting them up so that there's a balanced approach there?

To this Dr. Nelson stated that in his personal experience of obtaining organs, "the best guarantee...is the rapport the treating physician has with the patient and family at a time long before the problem or the question of organ donation comes up at all." He also mentioned that "it's very important that we maintain the integrity of the treating team and

⁵⁹³ *Ibid.*

the team involved in caring for the potential recipient. I think these have to be kept apart.”⁵⁹⁴ Mrs. Ur agreed, “I guess that’s what I was trying to say. That’s where you get the ethics in, when you have the two teams involved.” For this legislator, the *dividing practice* of separating doctors when mixing patients is a suitable means to ensure moral problems do not arise.

The comment made by the Member for Wanuskewin, Mr. Maurice Vellacott, in response to Dr. Oliver and Dr. Brear’s testimonies was as follows:

Mr. Maurice Vellacott: I have to be up front, I guess, and state that I had some questions or queries on the issue of brain death before, and now, probably more than ever, I have some reservations. I’m jolted, frankly, when we hear that we give anaesthetic to the so-called donor when they take organs from him or her.⁵⁹⁵

To this comment, Dr. Kluge interjected:

Dr. Eike-Henner Kluge: it may be important for you to know that the reason anaesthetics are given is not to kill pain. Anaesthetics also serve, as Dr. Nelson will point out, as vasopressor drugs, controlling all sorts of body processes. In fact, that is the major reason.⁵⁹⁶

Mr. Vellacott did not appear convinced, responding that although he was aware of that, “It’s just interesting to me that, for whatever the reasons, anaesthetics are required.” He requested Dr. Kluge provide him with the written criteria for brain death from the Canadian Medical Association. Calling into question public trust of doctors, he then asked whether physicians are still required to take the Hippocratic oath. Dr. Kluge replied: “no”.

His second question to the entire panel was whether signing consent to organ donation on a driver’s licence is informed “if the potential donor has not had the process or the procedure explained?” He argued that “My view of informed consent involves somebody sitting down and explaining what would occur, whether by slides, pictures or videos, to give a more graphic understanding of the process.”⁵⁹⁷ Dr. Brear replied that given the lack of access to knowledge of the debate surrounding the ‘brain death’

⁵⁹⁴ No. 67 (1155) Mrs. Rose-Marie Ur, Member of Parliament for Lambton—Kent—Middlesex

⁵⁹⁵ No. 67 (1155) Mr. Maurice Vellacott, Member of Parliament for Wanuskewin

⁵⁹⁶ No. 67 (1155) Dr. Eike-Henner Kluge, Chair, Dept of Philosophy, University of Victoria

⁵⁹⁷ No. 67 (1200) Mr. Maurice Vellacott, Member of Parliament for Wanuskewin

diagnosis, "nobody in Canada who signs a donor's card¹ has informed consent. Absolutely not." Dr. Rolleston and Dr. Nelson provided descriptions of what constitutes informed consent without answering Mr. Vellacott's question. Relaying his own experience, he told them:

Mr. Maurice Vellacott: I didn't know zip when I signed the donor part on my driver's licence. I didn't know anything. No doctor sat with me. I didn't know anything, or not as I do at this point.⁵⁹⁸

Dr. Kluge stated that "as a specialist in medical ethics," it should be clarified that the type of informed consent that applies in this situation is not subject to the same ethics because it is "for the disposition of your human remains," not for treatment. To this Dr. Oliver disagreed:

Dr. Ruth Oliver: Getting back to the brain-death issue, we don't know that they're dead. Most people would rest more if they knew for sure it was after.

As she had argued in an earlier interjection into questions to Dr. Kluge, checking off a box was for this reason not informed consent. Ignoring the possibility of wrongdoing just raised by Dr. Oliver, the meeting ended with a question by the Chair of the Committee to Dr. Kluge regarding the procurement system in Spain and right of the family to veto individual consent to donation. Members of Parliament thus resumed the discourse of donation with ease in spite of the counter-truth presented to them.

5.5 Repeating "the Truth"

The seven days of testimony that followed resumed consideration of the 'real' problems of the transplant episteme. In only one other instance did the issue of 'brain death' break through the discourse of donation. Of his own accord, Dr. Sam Shemie, Principle Investigator at the Hospital for Sick Children, included in this testimony a reminder about 'brain death'. At the eleventh meeting, he told the Committee,

⁵⁹⁸ *Ibid.*

Dr. Sam Shemie: ['brain death'] is defined as the complete and irreversible cessation of brain function that is medically and legally equivalent to death, in this country, in North America, and in many countries around the world. Regarding the diagnosis of brain death, first you have to recognize that it's there; second, you have to diagnose it; and third, you have to confirm it, and the confirmation has to be done by two separate physicians, at two different points in time, by rigid and strict criteria.

There are only two possibilities after brain death is diagnosed. That is death without organ donation or death with organ donation. There is no other choice. When a child or an adult is brain dead, that person will die. There is no question about that. The question is whether they die donating their organs or without donating their organs.

There are very few things that are black and white in life, but brain death is one of them. The issue is that we cannot change all the events leading to a child becoming brain dead. That is out of our hands...What we can change is what happens once that child is declared brain dead, in terms of the approach to the family.⁵⁹⁹

Mr. Keith Martin reinforced his remarks with praise: "Dr. Shemie, you did a very good job of articulating the issue of brain death, that somebody who is brain dead is indeed dead." He requested the criteria for brain dead used at Sick Kids Hospital be submitted to the Committee clerk. Dr. Shemie took this opening to reiterate to the Committee his view of 'brain death':

Dr. Sam Shemie: It is the complete and irreversible cessation of brain function. That means these patients are unconscious, they cannot think, they cannot feel, they cannot move, they cannot see, and they cannot breathe, and those functions will not recover.

There has been previous testimony in this committee meeting that somebody was previously diagnosed with brain death and yet is now alive and functioning. That cannot be true. The use of the term "brain death" is being used inappropriately or that person is misinformed.⁶⁰⁰

Keeping the question technical, he emphasized that "there are strict clinical guidelines for the examination to confirm brain death." Once again, he informed legislators: "So it's the complete and irreversible absence of brain function, both higher-brain cortical function and lower-brain brain-stem function, and those patients do not recover."⁶⁰¹

⁵⁹⁹ No. 71, March 17, 1999 (0925) Dr. Sam Shemie, Principle Investigator, Hospital for Sick Children

⁶⁰⁰ No. 71 (1015) Dr. Sam Shemie

⁶⁰¹ No. 71 (1020) Dr. Sam Shemie

Mr. Vellacott responded to these comments by defending the dissenters dismissed as misinformed by noting that one is a medical doctor with a specialty in psychiatry and the other a practitioner who is required to declare death.⁶⁰² He countered Dr. Shemie's testimony by stating that his understanding is that there is not a uniformity of definition for 'brain death' across the world. Howard Nathan, Executive Director of the Delaware Valley Transplant Program in Philadelphia explained that the standard is based on medical literature. Physicians in each hospital establish a standard of practice in the form of a protocol to apply in that institution. There could therefore be variance across hospitals. Regardless,

Mr. Howard Nathan: there's no question that without exception brain death is accepted as a standard of practice. There are people who claim they have had patients survive, and I think the committee has heard that. In 21 years of practice I have never been in a situation where someone who has been diagnosed as brain dead, whether or not they were an organ donor, survived. They are without question dead.⁶⁰³

Dr. Gordon Crelinsten, Chair of the Committee on Ethics at the CMA contributed by saying that the latest clinical guidelines for diagnosing 'brain death' come from the Canadian Neuro-Critical Care Group, which is made up of members of the Canadian Neurological Society, the Canadian Neurosurgical Society, the Canadian Association of Child Neurology, and the Canadian Society of Clinical Neurophysiologists.⁶⁰⁴ In noting the resources holding this truth claim in place, he implied that to call the diagnosis false is to suggest that each of these professional associations are wrong. Dr. Shemie reiterated his earlier statement:

Dr. Sam Shemie: Irrespective of the issue of organ donation, *once the diagnosis of brain death is made, that patient will die.* So if you separate out the issue of organ donation, that patient is still going to die. The issue is whether or not they die in addition to donating the organs... That is standard practice in North America and in many countries around the world.⁶⁰⁵

⁶⁰² No. 71 (1050) Mr. Maurice Vellacott, Member of Parliament for Wanuskewin

⁶⁰³ No. 71 (1100) Mr. Howard Nathan, Executive Director of the Delaware Valley Transplant Program

⁶⁰⁴ No. 71 (1055) Dr. Gordon Crelinsten, Chair of the Committee on Ethics at the Canadian Medical Association

⁶⁰⁵ No. 71 (1100) Dr. Sam Shemie (emphasis added)

Thus, although the Principle Investigator's point was that 'brain death' is death, he repeatedly distinguishes 'brain death' from death by stating that the 'brain dead' are dead and will die. More than a semantic confusion, this illustrates the detachment of embodiment from personhood as the crux of the matter. Nonetheless, the distinction made by 'brain death' between the end of personhood and biological cessation is not discussed. The dubious moral status of what used to be referred to as 'the twilight zone' does not pose a problem. Accuracy in applying the diagnosis remains the only possible uncertainty. When this is the case, more sophisticated tests are applied to establish the presence of this reality. There is no subjectivity to the interpretation of signs. Repetition of the 'fact' that 'brain death' diagnosis is widely accepted, normal and standard practice problematizes its very questioning by asserting it – as 'the way things are' – as legitimate.

Later in the same session, Dr. Rosalie Starzomski of the University of Victoria, an Ethics Consultant for the Vancouver General Hospital and Health Sciences Centre, told the Committee about a study that found the majority of nurses and physicians in Canada lacking knowledge of 'brain death'.⁶⁰⁶ Nonetheless, in response to a question posed by Mr. Vellacourt on whether the definition of 'brain death' should be liberalized, the ethicist and Organ Donor/Transplant Coordinator for the Ottawa Hospital-Civic Campus, Ms. Liz Anne Gillam-Eisen, reaffirmed the status quo as the only possible 'truth'.

Dr. Rosalie Starzomski: I think the definition of brain death we have currently is very adequate. I think what has happened, from my reading of some of the testimony that was given to this committee, as well as what's been reported in the media, is people have misinterpreted that very definition.⁶⁰⁷

Ms. Liz Anne Gillam-Eisen: Brain death, as it stands now, is death. The death certificate of a donor is signed and dated the time the donor is declared brain dead, not the time they're removed from the ventilator. If there's still some brain function, that is not death; the patient is not dead. We wouldn't be able to sign death certificates prior to removing patients from ventilators. I think as we stand now, the definition is death, and that's what we've been trying to educate health care

⁶⁰⁶ No. 71 (1135) Dr. Rosalie Starzomski, University of Victoria; Younger et. al. also found this in a study conducted in the 1980s. See Stuart J. Youngner, Seth Landefeld, Claudia J. Coulton, Barbara W. Juknialis, Mark Leary "Brain Death' and Organ Retrieval: A Cross-sectional Survey of Knowledge and Concepts Among Health Professionals." *JAMA* 261:2205-2210, 1989.

⁶⁰⁷ No. 71 (1225) Dr. Rosalie Starzomski

professionals about, and we need to obviously continue doing that in a better and more effective manner.⁶⁰⁸

From their perspective, any disagreement is ignorance that can be corrected by education. Instilling this 'truth', is, indeed, the job of organ procurement organizations. Any belief to the contrary is the challenge of their work.

This insistence was made in light of the research Dr. Rosalie Starzomski presented to the Committee which showed fewer health care providers (76 percent) than citizens (93 percent) in support of organ donation. This added evidence to Dr. Brear's claim of a burden placed upon physicians. Of health care providers, the largest group of non-donors were critical care nurses who work in transplant hospitals. Dr. Starzomski read a quote from a nurse responsible for caring for both donors and recipients:

'we have the donor [going] out and then the next day the recipient comes in, and I cannot switch my emotions. I just feel very tense inside and because I was still thinking of the family of the person who just passed away and then trying to think of, oh, this person got his transplant. I don't know, I just don't feel happy about that and I feel very worried. I just can't, you know have my emotions switched off, you know?'⁶⁰⁹

Mr. Vellacott asked about this noting that it contradicts the general assumption of earlier debates on informed consent and Dr. Starzomski's view that greater public education would increase the donor rate. The statistic brought into question the model Mr. Vellacott had in mind to show a video of the donation process to ensure consent was informed. If the people most exposed have chosen not to be donors, the outcome of more information would have the effect of lowering not increasing donation. The 'expert' responded:

Dr. Rosalie Starzomski: Not all of the people who work there are convinced that transplantation is a good thing. They're not all supportive of transplantation. What my study showed is that a number of critical care nurses have decided not to be organ donors because of the concerns they have about the transplant program in general.⁶¹⁰

⁶⁰⁸ No. 71 (1230) Ms. Liz Anne Gillam-Eisen, Organ Donor/Transplant Coordinator for the Ottawa Hospital-Civic Campus

⁶⁰⁹ No. 71 (1130) Dr. Rosalie Starzomski

⁶¹⁰ No. 71 (1220) Dr. Rosalie Starzomski

Although this indicated that refusal to donate may be based on something other than ignorance, her prescription for signs of resistance was support and education within intensive care units and at the institutional level of the hospital. She suggested that we need to open up a dialogue within those critical care units “in order to understand more about what’s happening and the lived reality of those nurses and why they believe being organ donors is not important for them.” Starzomski epitomized the “missionary-like ardour”⁶¹¹ of transplant advocates engaged in “converting” people to this secular ethical regime in taking this view of critical care nurses. Not being an organ donor - like not being a Christian - was incomprehensible from the world view of someone who believes that transplantation must happen.

5.6 Allowing Transplantation to Proceed

‘Brain death’ was not mentioned at all in the final three sessions. The Standing Committee on Health’s report “Organ and Tissue Donation and Transplantation: A Canadian Approach,” was, as planned, a reinforcement of the transplant episteme (hereafter referred to as the *Committee Report*).⁶¹² It called for a National Transplant Network to coordinate, integrate and oversee four program areas: individual donor intent, potential and actual donor identification and management; sharing, matching and allocation of donated organs and tissues; and transplantation outcomes.⁶¹³ This would operate as a permanent program area with a secretariat, appropriate budget and expert advisory groups “composed of members drawn from existing organizations involved in organ and tissue activity.” This ‘national body’ would function through the Federal/Provincial/Territorial Advisory Committee on Health Services, likely replacing the National Coordinating Committee on Organ and Tissue Donation and Distribution.

A section and recommendation was included in the *Committee Report* on ‘brain death.’ Although claims to give an account of what the Committee heard, the document

⁶¹¹ Fox and Swazey, 1992. *op.cit.* p. 204.

⁶¹² “Organ and Tissue Donation and Transplantation: A Canadian Approach” Report of the Standing Committee on Health, April 1999. *op.cit.* p. 46-48.

⁶¹³ *Ibid.* p. 59-65, List of Recommendations

reiterates Dr. Nelson's testimony almost verbatim. Drawing on his cultural capital as the 'expert', his views were clearly listened to and enroled in while others were ignored. Thus, the "Canadian approach" is to uphold 'brain death' as a 'black box': affirming its status as stable, reliable and protected from risk. Consideration of the rationale, need and legitimacy of this category of 'non-persons' is contained by the assertion that accuracy is the only question. As the input and output of the 'black box', it is the correct judgement of the presence or absence of 'brain death', that constitutes the only real concern.

In the *Committee Report*, the account of 'brain death' repeats Dr. Nelson's testimony. This begins with the claim of a need for a new locus of personhood in the body once machines could substitute for and prolong heartbeat and breathing. This lead to 1968 criteria "when it was proposed that death could be considered when the brain stopped functioning. Thus brain death was equivalent to death of the individual."⁶¹⁴ This idea - which had no name, or one ('irreversible coma') that faded away - is given the current name in the historical retelling of how a 'fact' came into existence. This conceals the controversy and uncertainty surrounding this concept by emphasizing the translations it underwent in the process of truth formation. Rather than debate and rejection in some places, the *Committee Report* states that the 1968 pronouncement "led to the establishment of committees throughout the world to set criteria for brain death."⁶¹⁵ Indicating the range of allies and resources that hold this 'truth' in place, the report states that in 1987 four Canadian medical professional organizations proposed criteria and updated them in 1992 to include neonates, infants and young children.

'Brain death' is explained on the basis of knowledge of the anatomy and function of parts the brain. Dr. Nelson's instructive statements of conditions that must be distinguished are repeated. To account for what 'brain death' is, the end of personhood is described in biological terms as "the irreversible loss of the capacity for consciousness combined with the loss of all brain stem functions including the capacity to breath."⁶¹⁶ Prior to listing the criteria for 'brain death' and qualifications to its application to children, the *Committee Report* explains how 'brain death' relates to organ donation.

⁶¹⁴ "Organ and Tissue Donation and Transplantation: A Canadian Approach" Report of the Standing Committee on Health, April 1999. *op.cit.*

⁶¹⁵ *Ibid.*

⁶¹⁶ *Ibid.*

First it is repeated that “the prevailing medical view considers that brain death is synonymous with death,” then the testimony of Dr. Shemie from the Hospital for Sick Children is repeated:

The outcome for the individual is death regardless of whether the patient will become an organ donor. The patient will be removed from all mechanical devices once brain death is established. Remaining on artificial support is not an option for a brain dead individual.⁶¹⁷

This is qualified by stating that “in cases where the individual is to be maintained as a donor, the artificial support measures are retained only in order to maintain the organs for donation.” As additional support for the implicit argument that ‘brain death’ is death, it is further noted that “the Committee learned that the time of death on the death certificate is recorded as the time of brain death diagnosis, not the time at which all artificial support is withdrawn.”⁶¹⁸

Taking an active position with respect to ‘brain death’, the Committee adopted Dr. Nelson’s advice on ways to improve the administration of the diagnosis as one of the 12 recommendations in the *Committee Report*. A paragraph was therefore included on strengthening safeguards. Dr. Nelson’s position that the only possible problem, “premature diagnosis,” is offered to frame the paragraph followed by reiteration of his instructions on how the diagnosis ought to be administered: requiring physician experience and the *dividing practice* of separate teams of physicians.⁶¹⁹ A doctor who performs the diagnosis of ‘brain death’ must “have no stake in the diagnosis; specifically it cannot be a transplant physician.”⁶²⁰ Including time periods for waiting until all the signs appear, this paragraph concludes by repeating Dr. Nelson’s directive that, “the diagnosis is never to be made hastily.”

⁶¹⁷ *Ibid.* p. 46.

⁶¹⁸ *Ibid.*

⁶¹⁹ It is notable, especially given Dr. Starzomski’s information on critical care nurses views of transplantation, that the division of medical staff applies only to doctors. Organ procurement coordinators are usually critical care nurses, which gives potential recipients a representative at the bedside of potential donors.

⁶²⁰ “Organ and Tissue Donation and Transplantation: A Canadian Approach” Report of the Standing Committee on Health, April 1999. *op.cit.* p. 47.

At the end of the section on 'brain death' is a two paragraph account of the dissent from this 'truth'. In contrast to the first section, this part uses qualifiers such as the number of witnesses and the attribution of emotion rather than descriptive terms.

The Committee heard from some witnesses that acceptance of the brain death concept is not universal. A few witnesses expressed the view that brain death is perhaps not synonymous with death of the individual but merely a state in which death is imminent and inevitable. Other testimony stated that doctors must be sensitive to the fact that there are groups and individuals that do not accept the concept of brain death.

Some testimony expressed doubts as to the infallibility of the diagnosis of brain death. This drew attention to the criteria followed for the diagnosis of brain death. A few witnesses feared that these criteria could be met while an individual was not actually brain dead. While the expert testimony on brain death did not dispute this, it was also pointed out that the diagnosis cannot be based solely on the satisfaction of the criteria. Attention to the safeguards eliminates the possibility of misdiagnosis. Several witnesses testified that recovery from brain death is impossible and that reports of recoveries from 'the diagnosis of brain death' were seen as examples of misdiagnosis.⁶²¹

In this summary, Dr. Yun's point of view that what needs to be asked: whether 'brain death' really "can be considered" or "is synonymous with" death, is mentioned but not addressed. The questions of meaning that he raised – of 'brain death' relative to death, in a cosmology that allows for only alive or dead – escape analysis by dismissing the weight of his criticism to a minority view. Sensitivity to multiculturalism replaces consideration of what lines of enquiry and domain of expertise – medicine, philosophy or religion – is appropriate to the question of death. Differences in belief, mourning rituals and expressions of grief are thereby not taken to be serious considerations which could stand in the way of the task to increase the organ supply. Furthermore, the unwillingness to engage in Dr. Yun's challenge to 'brain death' dismisses any consideration of the possibility of flawed assumptions or moral problems underlying the discourse and practice of removing organs for donation. The questions Dr. Yun raised about the relationship between embodiment and personhood were thus ignored.

⁶²¹ *Ibid.* p. 48.

Newspaper articles that reported what occurred at this meeting, made no mention of Dr. Yun's testimony.⁶²² Similarly, the less fundamental criticism of Dr. Oliver and Dr. Brear receives greater attention in the *Committee Report*. Their dissent, which did not explicitly question death as a technical phenomenon, was recounted and deconstructed in the second paragraph. Setting in opposition "doubts" and "fear" versus "expert testimony," the fallibility question is asserted to be one of accuracy. It is answered by stating that even though the medical profession and hospital protocols say otherwise, satisfaction of the criteria is insufficient. "Attention" to who administers the diagnosis, how many qualified professionals check and when this is done, "eliminates the possibility of misdiagnosis." By consequence, this 'social' response by legislators places greater reliance on "safeguards" than diagnostic criteria. This account restores the 'black box' by establishing only 'real' question as one of the presence or absence of 'brain death'. Majority opinion is cited as dismissing any view contrary to the prevalent view that 'brain death' is death as erroneous. Recovery from 'brain death' is not possible.

With this explanation for their position, the Committee recommended that their proposed national organization to oversee transplantation encourage:

Hospitals where donation takes place to develop clear protocols for determination of brain death, ensure professional and institutional accountability for each instance of a diagnosis, and provide thorough and periodic training for all healthcare professionals on the concept of and criteria for brain death.⁶²³

These measures ensure the consistent application of 'brain death' criteria to reinforce the 'fact' that the diagnosis itself is not a problem.

It is notable that the action item for this issue, to educate all healthcare professionals in the 'truth' of 'brain death' undermines the earlier acknowledgement that there are groups and individuals who do not accept the concept of 'brain death'. In spite of Dr. Starzomski's information regarding critical care nurses, the possibility that healthcare workers or citizens do not participate in this *technology of health* for legitimate

⁶²² See Mark Kennedy, "Brain dead donors 'alive': MDs debate ethics of transplants" *The Ottawa Citizen*, March 3, 1999. p. A3; Anne McIlroy, "From one who's been there: Don't alter organ-donation law: Health committee hears testimony of dangers of early 'harvesting'" *The Globe and Mail*, March 3, 1999. p. A2.

⁶²³ *Ibid.*

reasons is not considered. The moral duty to give, articulated through the discourse of donation, may make this thought not “amenable to being thought.”⁶²⁴ “If weighty – albeit unarticulated – reasons...underlie such refusals,” this would indicate a fundamental and possibly permanent barrier to the goal of increasing the donor rate.⁶²⁵ Instead of considering such possibilities, the Standing Committee reinforced the diagnosis for ‘brain death’ and limited the question of death to technical considerations. The unwillingness to consider another ‘truth’ reflects and strengthens the transplant episteme.

Even the sole legislator, Mr. Vellacott, the Member for Wanuskewin, who first opened the ‘black box’ of ‘brain death’, did not remain outside the transplant episteme. While responsible for enabling the dissenters to testify before the Committee, this MP also articulated a moral position in favour of donation throughout the hearings. While not party to efforts to encourage donation, Mr. Vellacott also did not extend a piece of legislation he introduced to the House of Commons in October of 1999 to medical practitioners such as Dr. Yun. Bill C-207, “to amend the Criminal Code to prohibit coercion in medical procedures that offend person’s religion or belief that human life is inviolable” covers only the beginning of life, not the end.⁶²⁶ Although the underlying argument of the legislation is the protection of personhood, and in both cases life and death are defined in terms of knowable ‘moments’ rather than processes, a moral stance that marks the beginning of life at an early stage is not matched by a moral stance marking the end of life at a late stage.⁶²⁷

By contrast, other Reform Party members sought to champion the cause of organ donation. Dr. Keith Martin, Mr. Germant Grewal and Mr. Reed Elley issued a Minority Opposition Report far stronger than the Committee’s Report.⁶²⁸ Mr. Elley, who was reported in a newspaper article to have a daughter who may need a organ replacement later in life,⁶²⁹ later introduced one of the Standing Committee recommendations to the

⁶²⁴ Nikolas Rose, 1994. *op.cit.* p. 63.

⁶²⁵ Gilbert Meilaender, 1996. *op.cit.* p. 32.

⁶²⁶ “Human life” is defined in the bill as meaning “at any stage beginning at conception.” Bill C-207. The House of Commons of Canada, 2nd Session, 36th Parliament, http://www.parl.gc.ca/36/2/parlbus/chambus/house/bills/private/C-207/c-207_1/362001bE.html

⁶²⁷ This contradiction is one, however, that some Christian fundamentalists have started to address by calling ‘brain death’ into question.

⁶²⁸ Mr. Greg Thompson from the Progressive Conservative Party was also a contributor to this Report.

⁶²⁹ Anne McIlroy, “Organ donation as issue that is close to MP’s heart: Youngest daughter, one of eight

House of Commons in Private Members Bill C-498. This piece of legislation sought to hold an annual public ceremony whereby the Governor General of Canada would award a Organ Donation Medal “to commemorate a person for the posthumous donation of an organ.”⁶³⁰ The medal, which “represents the respect demonstrated by the person towards human life and dignity,” would be received by the surviving “donor family.” Cultural capital rather than financial capital would thereby be bestowed upon Canadian citizens as an incentive. This would give them a status equal to soldiers who sacrifice their lives to save and protect the nation from losing a war – in this case, the war against disease.

5.7 Latour’s ‘Great Divide’

On the basis of their account of the evidence presented to them in the *Committee Report*, Members of Parliament justified their reasons for continuing to endorse and further invest in transplantation as a particular *technology of health*. They did not disrupt the ‘truth’ of ‘brain death’; they restored it to the status of ‘fact’ following an open challenge of its legitimacy. This was done by supporting the dominant medical view and claim that death is “scientifically deducible and verifiable” and subject only to scientific forms of authenticity.⁶³¹ While the terms ‘culture’ and ‘nature’ were avoided, death was presented as in no way inducing questions of an ontological kind.⁶³²

What is notable about this breaching moment is not what resulted from it as much as the way in which it was arrived at and presented as truth. It is how the ‘black box’ on ‘brain death’ was closed that exposed transplantation to be governed by an episteme. Legislators could have endorsed the use of the ‘living dead’ on other grounds. Whether a person is dead or not may not matter; prognosis rather than diagnosis may be adequate; the need for spare body parts may justify “killing” some dying persons as may a “conceptual gerrymandering” for this end.⁶³³ Or, a degree of uncertainty may be

children, may someday need a kidney” *Globe and Mail*, March 4, 1999. p. A4

⁶³⁰ Bill C-498, First Session, Thirty-sixth Parliament, The House of Commons of Canada “An Act respecting the establishment and award of an Organ Donation Medal to commemorate a person for the posthumous donation of an organ” First Reading, April 22, 1999.

⁶³¹ Margaret Lock, “Death in Technological Time.” 1996. *op.cit.* p. 577.

⁶³² *Ibid.*

⁶³³ Stuart J. Youngner “Defining Death: A Superficial and Fragile Consensus” *Archives of Neurology* 49:

sufficient in conjunction with certainty rituals such as recording the official moment personhood ends. Any of these possibilities may be sufficient grounds upon which those asked to donate may be willing to do so. But, with the exception of pockets of resistance, the way in which this social order has been constructed is firmly in place by 1999. And, it is strongly defended for all who stand to benefit from this way of seeking to cure.

At a micro level of analysis, the greater social status of those who articulated the dominant medical view justified the selective listening to 'experts'. Dr. Nelson represented several resources enroled in the truth of 'brain death': the Canadian Medical Association, the specialty of neurosurgeons, a university and large hospital. Dr. Kluge was affiliated with the federal government, the Canadian Medical Association and a university as a medical ethics expert.⁶³⁴ By contrast, although the three dissenters were physicians and specialists, they represented only themselves, not larger institutions or organizations. As a group, their voices did not, therefore, hold equal weight.

The type of evidence presented also contributed to the ability to set aside the view of the dissenters. Dr. Yun and Dr. Oliver's testimonies were experiential cases that could be dismissed as exceptions. Offering their views as stories, these presentations voiced "opinions held by particular individuals in the here and now of an event." This failed to "delete the modalities" that convert statement into 'facts'. Statements without modalities - no visible authors, identification of time or context - are far stronger by making invisible "all traces of social construction."⁶³⁵ Thus, Dr. Kneteman's declaration that "brain death is death" held more semantic sway in its definitiveness. In appearing to let reality speak for itself, this 'fact' is presented as timeless and universal and therefore more valid. The individuals who thought of the idea, the series of concrete events it underwent, and, the uncertainty and controversies that once surrounded the statement "brain death is death" (in chapter three) are not visible at the Standing Committee Event.⁶³⁶

570-572, 1992. p. 570.

⁶³⁴ Dr. Eike-Henner Kluge informed the Committee that he formerly held the post of director of ethics and legal affairs of the Canadian Medical Association and has completed a study for the Health Protection Branch, Health Canada.

⁶³⁵ See chapter one, pages 21-24; Latour, 1987 *op.cit.* p. 21.

⁶³⁶ Stephan Fuchs, 1992. *op.cit.* p. 47

Firm assertions of the ‘truth’ of ‘brain death’ were made by Dr. Kneteman, Dr. Spital, Dr. Dosseter, Dr. Eike-Kluge, Dr. Shemie, Dr. Nathan, Dr. Starzomski and two OPO representatives. Each of these statements of ‘fact’ along with direct interjections in response to the dissenters deconstructed and reversed their position. Representing the neutral authority of the medical profession, Dr. Nelson continually reinforced the view that the donor’s death is not an issue. These contributions to the issue served to close the ‘black box’ opened by the dissenters.

At a macro level of analysis, the power contained in these interactions demonstrated the presence and way in which Latour’s ‘Great Divide’ between the ‘social’ and ‘scientific’, as two distinct ontological zones, functions in Western society. Transplantation continued through the firm endorsement of its location on the scientific side of the divide. As a diagnosis, ‘brain death’ is a knowledge claim that was repeatedly asserted to be scientific. Its presence could be ascertained through the proper method of observation and applying ‘death tests’. This was in spite of at least one pro-transplant witness in each session of the seventh meeting acknowledging, in response to dissent, that ‘brain death’ was a philosophical point.⁶³⁷ Nonetheless, neither they nor legislators were willing to enter the “distinct ontological zone” of the social.⁶³⁸ Aside from Dr. Yun, only the rabbi engaged in the ‘social’ through his explanation of how ‘brain death’ was agreed to in Jewish medical ethics. This form of legitimation was not explored; it was avoided.

It went unquestioned that Dr. Nelson, the expert on ‘brain death’ stated that:

I will not go into the ethical philosophical matters of personhood and what constitutes the essence of an individual. Rather, I wish to focus on biological facts and explain how the average physician goes about trying to determine brain death.⁶³⁹

⁶³⁷ Support for Dr. Yun’s position came from Dr. Dosseter, “Now, whether the brain is dead means that the person is dead, as I believe, is a matter of some degree of philosophical and religious judgment” (0955); and Dr. Nelson: “I will not go into the ethical philosophical matters of personhood and what constitutes the essence of an individual.” (1105)

⁶³⁸ Bruno Latour, 1993. *op.cit.* p. 101.

⁶³⁹ No. 67 (1105)

Medical scientists are not required to think beyond the technical dimensions of organic life. All that is 'social' is set aside, "as extraneous and irrelevant to the *real* biomedical diagnosis."⁶⁴⁰ Although 'natural' was a word absent from all reference to organ removal, this 'purification' renders the 'brain death' diagnosis amenable to being thought of as normal. Through the ability to dismiss the "philosophical," the historical uncertainty, controversies and normative commitments (linked from 1968 onward to suggest that the cessation of the brain rather than the heart be interpreted as a sign indicating the end of personhood) that make up the present are rendered absent from this forum. Who is to take up such questions, that physicians and scientists are free of, and what role they hold – if any – is not asked.

Concerned legislators reinforced the factuality of 'brain death' in response to dissent by seeking assurance that the diagnostic criteria are infallible. Legislators (Ms. Picard, Ms. Minna, Ms. Ur and Mr. Vellacott) demonstrated the alignment of the state to the transplant episteme through their unwillingness to hear anything other than confirmation that the classification was firm. This reflects the use of science by legal and governmental agents to provide answers to facilitate difficult decision-making. Absolute certainty seen to be accessible through this form of authenticity is offered as justification for particular positions. Although described as a concept in the *Committee Report*, legislators reinforced the claim that 'brain death' can be scientifically knowable and calculable.⁶⁴¹ As such, the diagnosis itself was once again presented as unproblematic. The irony of this position was failing to recognize 'brain death' as a social choice while implementing 'social' "safeguards" regulating the administration of the diagnosis.

Why dissent was countered also contributes to an understanding of how this challenge could be marginalized. From the outset, shifting attention away from the chimera/recipient to consider the natural resource/donor and their status as alive or dead, person or non-person or something in-between proved to be difficult. The Study on "the State of Organ and Tissue Donation in Canada" was initiated upon the consensus that transplantation is an unquestioned good. This positioned legislators as holding a normative commitment firmly tied to the fate of those dying organ-first; with the task to

⁶⁴⁰ Nancy Scheper-Hughes and Margaret M. Lock. 1987. *op.cit.* p. 8.

⁶⁴¹ Collins, Kendall and Michael, 1998. *op.cit.* p. 9.

recommend the best means to improve the service of providing organs. The dissenters had no range of allies and resources on their side compared to one hundred witnesses, representing sixty-seven organization and institutions who testified in support of this *technology of health*. This included the authority of transplant physicians, the federal and almost every provincial government, the medical profession and public hospitals. Thus, the inconsistent and sometimes contradictory information on criteria for declaring 'brain death' and which dying patients are being used as donors, lack of consideration of the inner workings of the medical profession and a lack of information on the consistency of hospital protocols, did not matter. The sheer weight of endorsement of "organ donation" was sufficient to ensure 'brain death' retained its status as fact.

There was too much moral and economic capital invested in organ harvesting in 1999 to successfully challenge the transplant episteme. Public deliberation to collectively decide when in the continuum of disintegration personhood ended did not occur in Canada, as it did to varying degrees elsewhere.⁶⁴² However, the consequence of failing to uphold the basis upon which donation consent has already been accepted – as "after death" – at this point is too great. To do so would imply the complicity of every transplant centre, medical professional and, to a lesser degree, recipients in doing something fundamentally wrong. Having constructed this reality, as a way of enabling this *technology of health*, with a heavy degree of investment contributing to over thirty years of practice, it must be defended. Moreover, to bring into doubt the use of the dying would halt the entire purpose of the Standing Committee Study: to increase the number of donors. A challenge must be dismissed "in order for normal science to proceed."⁶⁴³ To accept the dissent that the 'brain dead' are not a legitimate source of organs would be politically dangerous for legislators given the broad consensus built around the issue of 'donation' by the transplant health campaign.

Separate from what is holding the truth of 'brain death' in place, it is possible that a dislike for the history and divisiveness of public debate surrounding the beginning of life in North American society may create a reluctance to consider personhood questions with respect to the end. Even though the advocate of this form of enquiry at the hearings

⁶⁴² See chapter three, section 3.4

⁶⁴³ Stephan Fuch, 1992. *op.cit.*.

articulated a Buddhist view of ontology, it is Mr. Vellacott's group, the Christian right, who are small but powerful enough to threaten the transplant episteme's use of the dying. Given the stronghold of this group, a scientific form e may be seen as strategically preferable to opening up another field for moral claims to be made against the interest of those in need of a medical service.

5.8 Conclusion

Although legislators varied in their response, none took the possibility of another reality seriously enough to alter the transplant episteme. Thus, it remains true that some people do become 'brain dead'. But, 'brain death', and 'brain death' as death, are only possible within the confines of the transplant episteme.⁶⁴⁴ In surviving this challenge, the episteme is reinforced and strengthened.

The role of the 'Great Divide' is clear in the asymmetry of statements given by witnesses and legislators. 'Brain death' as death is just as much a belief as 'brain death' as life. Scientific evidence cannot determine what is recognized as "a philosophical issue," it can only be used to this end. Nonetheless, 'brain death' solves a problem: when to pull the plug and how to attain spare parts for transplantation. The cost, however, of limiting the basis on which 'truth' can be questioned is to define the realm of the possible in such a way that 'the way things are' and 'the direction things are heading' is incontestable.

⁶⁴⁴ Steven Ward, 1996. *op.cit.* p. 17

Summary and Conclusion

This thesis has demonstrated that it is the way in which thought and practice regarding a particular therapeutic modality have come to form an epistemic reality that societal choices regarding matters of life and death are determined in the year 1999. The incident, referred to as the Standing Committee Event, that framed this analysis is the dissent of three doctors at a public forum held by the House of Commons during a study on the "State of Organ and Tissue Donation in Canada" by the Standing Committee of Health in 1999. The question posed in relation to what took place is how it was possible to marginalize a challenge to a central premise of transplantation - that organs are removed only from the dead?

The key to understanding what happened at the Standing Committee lay in asking how "organs and tissues" became a problematic of the present. Concomitantly, it was asked how speaking about body parts without mention of persons had come to be normal and unquestionable. The analytical tools found to be of use to this task combined Nikolas Rose's lines of enquiry with actor-network theory. Dimensions through which to examine the role of medicine in the "invention of the social" and the concept of truth formation through network construction provided the means to examine how transplantation came to be and is currently conducted.⁶⁴⁵ Viewing truth as a "temporary expression of knowledge/power," this lens was also suitable as an approach inherently conscious of temporal and spatial specificity.⁶⁴⁶

Embarking upon this analysis required first and foremost a conceptual and pragmatic account of the social relations of transplantation. Chapter two thus began by asking how the replacement of vital parts using the 'living dead' became a therapeutic modality. Rather than accept the view that the only thing to know about this way of seeking to cure is its possibility, the 'black box' of this *technology of health* was opened up by investigating the origins and motivations of this therapeutic modality. This revealed two matters of significance: that inherent to this way of seeking to cure is the positioning of life as dependant upon death; and, that the transplant industry is not free of

⁶⁴⁵ Nikolas Rose, 1994 *op.cit.* p. 55.

⁶⁴⁶ David Armstrong, 1994. *op.cit.* p. 17.

vested interests and non-altruistic motives. These findings were arrived at by tracing the history of transplantation as a *technology of health* through two distinct phenomena which 'opened a clearing' to make vital body parts replaceable: accessing the dead for dissection and making body parts transferable between live persons. It was demonstrated that it is not the "discovery" of transplantation but the alignment of religion, capitalism and the state to medicine that enabled replacement to become a possible way of seeking to cure. First, the conceptual and administrative means through which the dead were accessed for dissection initiated the separation of personhood, as the living body of an individual human being, from embodiment. Second, medical innovation seeking to develop new therapeutic techniques moved from 'live to live' transfers of blood and kidneys to the use of the 'living dead' for hearts, livers, pancreas, lungs and by 1999 thirty-nine other body parts to treat as many as twenty-six different people. Over time, objections to "playing God" and "artificially prolonging life" faded away as the capitalist economy, the state, medicine, law and religion aligned in support of the technology of replacement. The feasibility of a treatment for terminally ill patients dying organ-first led to an imperative to create the chimeric body. For this to occur, another patient had to become a natural resource.

With an analysis of how transplantation works and the forces driving the necessity to produce the chimeric body, chapter three and four turned to the natural resource body to demonstrate how a source of organs became available in the West when it did not elsewhere. In the late 1960s, transplant surgeons debated when death could be declared, whether a definition was even necessary and by what infallible evidence their colleagues could be convinced to amputate live organs from the dying. The release of a diagnosis for death based on the brain was not rejected in the West but used, updated and refined over the next thirty years. Controversy thus moved to 'fact' through the enrolment of more powerful actors and techniques of serious speech employed to produce authoritative knowledge. Public deliberations and legislation on the question of 'brain death' occurred elsewhere but not in Canada, with the exception of Manitoba. Passive support came about as a consequence of jurisprudence, a desire to resolve the 'cyborg situation' and, eventually, by conceding to medical authority on the basis of routinization. As a strong truth, accepted by the 1990s as a 'fact', the creation and controversies that hold 'brain

death' in place were 'black boxed'. Based on this tracing of science-in-the-making, I argued in chapter three that acquiring the status of 'fact' legitimated the removal of vital organs from the 'living dead' by making a stage of disintegration in the process of dying a visible category of 'non-person'. Historical excavation uncovered how taking organs from certain dying patients came to be accepted and normalized. Opening up this 'black box' shows that "it is the implications of the diagnosis that provide its rationale."⁶⁴⁷

How the meaning attributed to transplantation functions to mobilize participation in this therapeutic modality is the subject of chapter four. Rather than presenting transplantation as a utilitarian practice that "capitalizes organic life,"⁶⁴⁸ the replacement of organs has been presented as a morally praiseworthy act known as 'organ donation'. Here it was shown how, in addition to a legitimating mechanism, an economy of representation provides a justificatory mechanism to support the transplant episteme. Initiated by defining 'the body' as a 'gift' in law, a discourse of donation developed and solidified over the next thirty years. Coinciding with the politics of neo-liberalism, access to the 'living dead' was accomplished through the stimulation of a desire to donate. By taking up the cause of 'organ donation', allies formed to launch "awareness campaigns" and establish methods of surveillance to monitor the number of organs procured. The language of 'donation', and category of 'potential donor' in particular, mobilized the adoption of new medical practices within intensive care units to find, treat and remove parts of the body of one patient for another. Gaining the co-operation of the public and medical professionals thus succeeded by the emergence of 'organ donation' as an ethical secular regime that gives meaning to citizens seeking to aid the ill and prevent death. This argument shows one of the main insights of this thesis: that the effect of this positioning of transplantation is to 'black box' any questions about what drives the therapeutic technique and, by treating it as unproblematic, to further 'black box' the 'fact' of 'brain death' as death.

Examining the constituent parts of the transplant episteme brought into view the strength and range of allies that were marshalled on one side of the contestation that emerged at the Standing Committee Event in 1999. In direct response to the dissent by

⁶⁴⁷ Stuart J. Youngner "Defining Death," 1992 *op.cit.* p. 570.

⁶⁴⁸ Rosi Braidotti, 1994. *op.cit.*

three witnesses that 'brain death' is not death, legislators turned to medical and ethics 'experts' who re-asserted the 'truth' through claims of authoritative knowledge. Latour's 'Great Divide' of Western epistemology, distinguishing 'scientific' from 'social' ways of knowing, was utilized to this end through the continual assertion of medicine/science as the only appropriate form of authenticity and an unwillingness to engage in a philosophical consideration of death. The rationale, need and legitimacy of this category of 'non-persons' was thus contained by the assertion that the only 'real' question is accuracy of the diagnosis. Overall, it was the hegemony of the discourse of donation throughout the hearings that enabled the transplant episteme to continue. 'Brain death' must be death in order for 'organ donation' to continue. Power was thus exercised to close the 'black box' of 'brain death' opened up at the hearings. This breaching moment exposed the underlying "battle over the body" going on and how it was possible for this confrontation to turn out as a "win" for the transplant episteme through the deconstruction and marginalization of dissent. As a result, the "Canadian approach" to transplantation is for this way of seeking to cure to proceed to create natural resource bodies in order to make chimeric bodies.

Conclusion

What this thesis demonstrates is that there are concerns regarding the way in which transplantation is practiced in Canada that are marginalized from public debate. When one of several possible critiques of transplantation emerged at the House of Commons Event, it was dismissed. While the benefit of lives improved and continued in the face of death is clear, this thesis points out the cost of conducting transplantation in an epistemic fashion which is to render out-of-range concerns that suggest any potential of wrongdoing. In other words, a failure to distinguish a humane desire from a particular means results in the inability to take a position which questions how we try to cure. By enabling us to see the spatially and temporally specific creation of a therapeutic modality, the 'fact' of 'brain death', the adjustments in meaning and medical practice brought together through the exercise of power to facilitate a particular way of seeking to cure, this thesis shows how things could be different. It thereby 'opens up' and offers a

starting point for discussing whether this is the way in which "we" in the West or in Canada desire or are willing to seek to cure the ailing.

In tracing the 'history of the present', it was necessary to develop new concepts and analyses within chapters two, three and four which are original contributions to current research on transplantation as well as medicine, biotechnology and political economy. First and foremost is the idea of the 'chimeric' and 'natural resource' bodies as two kinds of bodies produced through transplantation. Articulating the connection of these two bodies through death order, definitions of death, the 'double medical gaze', categorical constructs and normative commitments illustrates how this way of seeking to cure connects individuals within populations. What is unique to the concept of these two 'types of bodies' is that they enable an analysis of biotechnological medicine that is inclusive of the source of cure.

Chapter two forges new ground in offering a theoretical account of transplantation based on the history of techniques used to cross the boundary of bioindividuality. It is shown that mixing two distinct genetic entities is possible without organ rejection by following a principle of (cellular) sameness, suppressing difference (using immunosuppressant drugs) and inducing sameness (through chimerism). The need to see oneself as the 'same' enough to others to cross the self/other distinction by using another's organ sheds light on another possible reason, based on Margaret Lock's research, that many Japanese - who are conscious of their blood type - are ill at ease with transplantation.⁶⁴⁹ The broader significance of recognizing the role of generic-ness in transplantation is to provide an alternative view of the utility of cellular and genetic research currently underway which is largely understood to be mapping uniqueness. If the pattern identified here is followed whereby research for knowledge led to efforts at replacement, it is relevant at this point in time to call attention to the existence of a therapeutic modality ready and able to move genetic research to genetic manipulation through transplantation. A move towards replacing cells and genes, instead of or in addition to new chemical therapies would increase demand for the natural resource body.

Chapter three adds to current research by tracing the inscription of the idea of 'brain death' as it becomes stronger and more resilient in Canada. The passivity of this

process and role of the law in conceding to medicine raise questions of representation and democracy. A fourth original contribution made in chapter four is the idea of the discourse of donation. This thesis demonstrates how the economy of representation attendant to a therapeutic modality mobilizes participation, inscribes meaning, and keeps 'black boxes' closed. Attention to the creation of categories - particularly that of the 'potential donor' and institutional regulation - adds to Ruth Richardson's identification of a parallel between accessing bodies for dissection and accessing bodies for transplantation.⁶⁵⁰ The result of the emphasis on donation as a moral imperative, shown in chapter four, is to cast some deaths - organ-first - as preventable and others deaths - brain-first - as acts of fate.

Through the sub-argument of a detachment of embodiment from personhood weaved throughout each chapter, this thesis incorporated another level of analysis into tracing the way in which the material practice of using and reconstituting bodies is fused to particular social constructions of representation and meaning. What stands out in observing transplantation from this point of view is how a fundamental shift in the use of human beings is being accomplished by the construction of a definition of death in the absence of a willingness to acknowledge death as provoking questions of an ontological kind. As demonstrated in this thesis, the key to this process is found in the linking of conceptual and administrative means applied within institutions to access bodies through the creation of categories ('vegabond', 'potential donor', 'brain dead'). A central effect is the rationalization of social relations of death by marking the 'real' as the diagnosis (with even the movement of the body interpreted as extraneous and irrelevant), and, defining the meaning of the end of life in the name of the health of others.⁶⁵¹ The argument of the transplant episteme provides another possible answer as to why the self/body, alive/dead and self/other boundaries crossed by this therapeutic modality along with the "cumulative inclusion of more and more body parts in the category 'nonessential to personhood'" have yet to "have the cumulative effect of straining notions of bodily integrity to the breaking point."⁶⁵²

⁶⁴⁹ Margaret Lock, "Reaching Consensus About Death," 1989. *op.cit.* p. 19-20.

⁶⁵⁰ See chapter two, section 2.1.

⁶⁵¹ Nancy Scheper-Hughes and Margaret M. Lock, 1987. *op.cit.* and Nikolas Rose, 1994. *op.cit.*

⁶⁵² Donald Joralemon, 1995. *op.cit.* p. 347.

What is original about the approach taken in this thesis is the development of an account of power as exercised in an epistemic fashion. Future research would apply this approach – which I see as a type of ethical analysis I call ‘embedded’ – to other ‘problems’ of medical intervention. The task of such work would be to take a step (in one of many possible directions) ‘outside’ to illuminate the framework within which standard ethical dilemmas arise. By uncovering ‘what holds the present in place’, embedded within common debates (of genetics or reproduction, for example), the aim of this approach is to illustrate that it is the way we have come to think and act upon a problem that ought to be the focus of our attention. It is the framework of choices and debate structured around particular ‘problematics’ that act as forms of power and shape social relations. As uncovered for the case of transplantation, the language used to speak about what we know, the categories created, the distinctions, normative commitments and all that is taken for granted is that which must be subject to investigation in order to understand how and why a particular problem emerges at a specific time and place. It is this kind of exposé of the problems that confront us – to ‘see’ what they conceal – that offers the possibility of forming other ways of doing things which may be more desirable, and, which will not occur through the acceptance of how to think about the world around us as conveyed by those more powerful than ourselves.

Appendix A Body Parts Used as Therapeutic Tools**December 2000**

blood	hand
sperm	forarm
ova	femurs
bone marrow	tibias
heart	fibulas
liver	patella
lungs	pelvic bones
pancreas	ribs
small bowel	humerus
kidney	rotator cuffs
cornea	calcaneus
dura mater	tendons
embryos	cartilage
“stem cells”	heart valves
foreskin	saphenous veins
umbilical cord	talus
brain tissue	meniscus
fetal tissue	femoral veins
pituitary gland	fascia
skin	

Appendix B Summary of the House of Commons Event

Hearings held by House of Commons Standing Committee on Health
 “Study of the State of Organ and Tissue Donation in Canada”
 February 2 to March 24, 1999

Mtg Date	Main Presenters	Key Topics Discussed
61 Feb 2	Federal government	Efforts to increase supply
62 Feb 4	Disease groups	Need to increase supply; family vs. indiv consent
63 Feb 9	Individuals	Personal stories of the need for organs
64 Feb 11	Provincial OPOs	Challenges to increasing supply (1 st dissent)
65 Feb 17	Transplant surgeons	Reasons for inadequate donor organ supply
66 Feb 18	Body part banks	Procurement systems: registries, safety, supply
67 Mar 2	Individuals and experts	Dissent (see chapter five)
68 Mar 4	Hospitals & regulators Ethicist	Monitoring “donation services” Xenotransplantation, informed consent
69 Mar 9	Donation co-ordinators	Efforts to increase supply
70 Mar 11	B.C. & Alberta gov.s	Procurement system; intended donor registries
71 Mar 16	Medical associations Transplant/donor experts	Need for organs (‘brain death’ ‘truth’ repeated) Procurement system comparisons (donor rate)
73 Mar 18	OPO, CORR, fed gov	Procurement system, interprovincial billing
74 Mar 23	OPOs: Spain, USA, Can	Procurement system comparisons (donor rate)
76 Mar 24	Can Blood Services MRC, CCOHTA	Research; Canada’s blood and bone marrow supply systems

(Meeting 72 and 75 were held *in camera*)

April report: “Organ and Tissue Donation and Transplantation: A Canadian Approach”

OPO - Organ procurement organization

CORR - Canadian Organ Replacement Register

MRC - Medical Research Council (Canada)

CCOHTA - Canadian Coordinating Office for Health Technology and Assessment

Appendix C List of Sources

Primary Sources

House of Commons

Notice of Motion, M-222, Journals No. 014, House of Commons of Canada, 36th Parliament, 1st Session.

Bill C-207, House of Commons of Canada, 36th Parliament, 2nd Session

http://www.parl.gc.ca/36/2/parlbus/chambus/house/bills/private/C-207/c-207_1/362001bE.html

Bill C-202, House of Commons of Canada, passed in 1997, declaring the last week of April national Organ Donor Awareness Week

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Bill C-498, House of Commons of Canada, 36th Parliament, 1st Session “An Act respecting the establishment and award of an Organ Donation Medal to commemorate a person for the posthumous donation of an organ” First Reading, April 22, 1999.

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