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## ON SILENCING AND SLICING: PRESUMED CONSENT TO POST-MORTEM ORGAN "DONATION" IN DIVERSIFIED SOCIETIES

*Marie-Andrée Jacob*<sup>†</sup>

### I. INTRODUCTION

Organ donation and transplantation is the site of a powerful convergence of professional and patient interests. The professionals are keen to apply new technologies, particularly ones that have dramatic effects and even a "magical" character.<sup>1</sup> Patients are interested in prolonging life, and in the ambiguous, yet enticing promise of improving its quality. But post-mortem organ procurement often runs the risk of disturbing the human sensibility in respect to our relations with our bodies, with death, and with mourning.

Although the original narratives of organ donation, with their connotations of gift giving, still resonate today in people's minds, in donors' minds, the current, more practical goal of organ procurement systems is the public need to solve the shortage of organs: to ensure that the supply meets the demand. In this complex mix of ambition, hope, and ruthless calculation, it is ethically and legally difficult to control the development of organ donation.

In the general area of health care and research, which includes organ and tissue removal, health professionals must obtain the

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1. See NORA MACHADO, USING THE BODIES OF THE DEAD: LEGAL, ETHICAL AND ORGANISATIONAL DIMENSIONS OF ORGAN TRANSPLANTATION (1998).

threshold of informed consent of the patient or subject.<sup>2</sup> However, the suggestion has been made that societies that practice organ transplantation could legally *presume the consent* of potential organ suppliers, unless the supplier rebuts the presumption.<sup>3</sup> This paper addresses the issue of presumed consent as an organ procurement strategy and examines whether it is an ethically sound policy for diversified societies.

The exploration of the ethical foundations of the doctrine of presumed consent is briefly presented, as well as examples of its legal implementation. Part II presents deliberative ethics on the issue. Part II also presents a sensitive approach to cultural difference. Both approaches consequently inform the analysis and critique of presumptions of consent to post-mortem organ donation in Part III. Part III tackles the problems with presumptions of consent. Using A. John Simmons' account of consent theory, presumed consent is probed for its association with tacit consent and consent by inference. From there, using the theoretical approaches presented in Part II, Part III queries the realistic possibility that a society can presume tacit deliberate undertakings. Additionally, Part III examines the concrete implementation of presumed consent and the mechanisms proposed to reverse the presumptions. Part IV complicates the issue, as most of the criticisms against presumed consent hold up just as well against an informed consent scheme: default rules present problems as they come up against delicate matters deserving considered decisions by each individual. The article ends by suggesting that if there is no "best default rule" in this area, there could still be one of "lesser evil."

This paper does not deal directly with the issue of the allocation of transplantable organs. In the context of organ donation and transplantation, while *procurement* is the process of obtaining organs,

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2. In Canada's common law jurisdictions, for example, this threshold has three requirements: first, the patient has to be informed about the procedure to be performed; second, she must be informed of possible consequences of the procedure; and third, health professionals must inform the patient of any alternative treatment. *Reibl v. Hughes*, [1980] 2 S.C.R. 880; *Ciarlariello v. Schacter*, [1993] 2 S.C.R. 119. When the procedure to be performed is research-oriented rather than therapeutic, the threshold is higher still. Subjects must have comprehensive and honest disclosure of all facts (i.e. probabilities and opinions that a reasonable person should have in order to consider being a research subject). Furthermore, the benefits of the procedure must outweigh its risks. *Halushka v. Univ. of Saskatchewan*, [1965] 53 D.L.R. (2d) 436.

3. See Jesse Durkeminier Jr., *Supplying Organs for Transplantation*, 68 MICH. L. REV. 811 (1969).

*allocation*<sup>4</sup> refers to the process of, and criteria for, determining who should receive the donated organs. Allocation has been demonstrated to favor privileged members of society.<sup>5</sup> In my view, the demand for organs and an equitable allocation system can be assumed. Working from this premise, this article is only concerned with organ procurement. However, when distributive concerns are raised with respect to organ procurement, the procurement patterns must be evaluated against allocation patterns. Thus, the latter will be briefly addressed when appropriate.

## II. PRESUMED CONSENT THEORY

The literature of presumed consent has introduced the terms “contracting-out” (or “opting-out”) in relation to organ procurement. In a “contracting-out” system, “organs may be removed after death unless individuals positively indicate during their lifetimes that they did not wish this to be done . . . .”<sup>6</sup> Everyone is automatically considered a donor after death, unless they have affirmatively withdrawn themselves from the pool of donors.<sup>7</sup> In this system, the rule and routine is donation.

### A. Ethical Grounds

Presumed consent can be justified by a communitarian vision of the world. Communitarianism rejects a liberal construction of the

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4. Allocation relates to the efficacy and benefits of transplantation, but also raises diverse issues, including those related to resource allocation and management in general. In this paper, I will not discuss the benefits of organ transplant in relation to extending an individual's life or providing good quality of life. Issues of allocation of scarce medical resources and of health services management are also beyond the scope of this article. I must also state that the purpose of my research here was not to analyze issues pertaining to recipients and specific categories of recipients based on age, gender, ethnicity, geographic area, economic status and health status.

5. Michelle Goodwin, *Deconstructing Legislative Consent Law: Organ Taking, Racial Profiling & Distributive Justice*, 6 VA. J.L. & TECH. 2 (2001); see also DAVID PRICE, *LEGAL AND ETHICAL ASPECTS OF ORGAN TRANSPLANTATION* (2002); Alasdair MacLean, *Organ Donation, Racism, and the Race Relations Act*, 149 NEW L.J. 1250 (1999).

6. I. Kennedy et al., *The Case for “Presumed Consent” in Organ Donation*, 351 THE LANCET 1650 (1998), available at 1998 WL 14104066.

7. In other words, to “opt-out” to the appropriate body (i.e. a computer registry, a box to check on driver's license, or a note in hospital files).

individual as an "unencumbered self."<sup>8</sup> Communitarianism focuses on the interconnection, interdependence, and community-orientation of beings. Following the Aristotelian tradition, Communitarian theory suggests that ethics is "the exercise of a set of spatially and temporally bound virtues that we may regard as our primary defense system against the destruction or erosion of that human community without which our lives would be aimless."<sup>9</sup> According to a communitarian, *her* organs might well belong to her during *her* life, as they are essential in that lifetime; but when no longer needed by or useful to her they are properly shared with the other community members. This "sharing of the goods"<sup>10</sup> is required, according to Aristotle. "[T]o be [human] is to fill a set of roles each of which has its own point and purpose: member of a family, citizen, soldier, philosopher, servant of God."<sup>11</sup> To this list, "organ supplier for your sick fellows" can be added. Sharing is a higher value than an individual's wish to preserve the integrity of a dead body.

Communitarians would approve of an across-the-board presumed consent rule because the donation of organs would be the *norm*. As reported by Nora Machado, "[n]ot to donate is a *negative deviation* from the norm. Since the norm is viewed as a positive act, the deviation becomes a negative and egoistic act,"<sup>12</sup> thus fulfilling the educational purpose of the law. Moreover, in order to effect the deviation, steps must be taken; contrasted with the passive obedience of the moral norm. Is it possible that a law or policy presuming consent will facilitate altruistic behavior, as it becomes easy to donate organs?

There are practical advantages to this method. If more organs are desirable, people are more likely to passively concur (the "status quo bias") and obey established routine. Without presumed consent, they must perform an active, and to some extent, energy-consuming altruistic act. In a world of presumed consent, "[i]nstead of altruism,

8. See M. G. KUCZEWSKI, FRAGMENTATION AND CONSENSUS: COMMUNITARIAN AND CASUIST BIOETHICS (1997); see also ALASDAIR MCINTYRE, AFTER VIRTUE: A STUDY IN MORAL THEORY (2d ed. 1984); see also E. J. EMANUEL, THE ENDS OF HUMAN LIFE: MEDICAL ETHICS IN A LIBERAL POLITY (1991); see also E.H. LOEWY, MORAL STRANGERS, MORAL ACQUAINTANCE, MORAL FRIENDS: CONNECTEDNESS AND ITS CONDITIONS (1997); see also MICHAEL J. SANDEL, LIBERALISM AND THE LIMITS OF JUSTICE (1982).

9. ROSEMARIE TONG, ETHICS IN POLICY ANALYSIS 86-87 (1986); see also MCINTYRE, *supra* note 8.

10. See KUCZEWSKI, *supra* note 8.

11. MCINTYRE, *supra* note 8, at 59.

12. MACHADO, *supra* note 1, at 193.

one articulates a notion of quasi-civic duty in donating organs, grounded on notions of social solidarity in society," writes Machado.<sup>13</sup> Another author speaks about presumed consent as being an expression of "presumed solidarity."<sup>14</sup> The assumption is that current human ethical behavior of lower priority between individual self-development and solidarity, or freedom and responsible involvement. As such, building a presumption of solidarity into the law would be ethically justifiable.<sup>15</sup>

On the other hand, presumed consent could alter the very meaning of the act of donating organs. What used to be an altruistic act could become routine. Another label for presumed consent is, in fact, "routine salvaging." Organ procurement could lose its solidarity component, since it would have no "donation" ethos. Since presumed consent bets on passivity, it may be unlikely to actually encourage active altruism. Some would say this is better than nothing, and that minor increases of altruism on the passive level helps people to help others, which is good. Yet there is a philosophical breakdown in the theory. One of presumed consent's underlying rationales is that it is easier to have people do nothing, rather than have them take any positive step to reverse the presumption by registering a refusal to donate. Yet betting on passivity is qualitatively different from presuming consent.<sup>16</sup> The ease of smoothly targeting inactive or uninformed citizens as potential donors has disturbing qualities: "[i]f one allows the existence of situations which *easily* generate donors, an illegitimate aspect of organ removal by presumed consent arises."<sup>17</sup> The inherent desire to do things rapidly and efficiently, and the possible manipulation of donors, is ethically troublesome, as elaborated below.

However, Maxwell Mehlman writes that presumed consent arguably "allows people to fulfill their altruistic will by refraining from objecting, which is psychologically easier for them than having to

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13. *Id.* See also Hanoeh Dagan, *In Defense of the Good Samaritan*, 97 MICH. L. REV. 1152 (1999).

14. P. Schotmans, *Responsible Involvement on a Large Scale: The Gift of Life in Implicit Solidarity*, in ORGAN REPLACEMENT THERAPY: ETHICS, JUSTICE AND COMMERCE (W. Land & J. Dossetor eds., 1991) [hereinafter ORGAN REPLACEMENT THERAPY].

15. *Id.*

16. A. Mendes & H. Alves, *Organ Donation by Presumed Consent: Consequences and Duties to the Society That Legalizes It*, in ORGAN REPLACEMENT THERAPY, *supra* note 14, at 281.

17. *Id.* (emphasis added).

give their express consent."<sup>18</sup> He bases this conclusion on the fact that people "really want to donate their organs, or those of their loved ones, but for psychological reasons cannot bring themselves to do so."<sup>19</sup> Presumed consent, "[b]y eliminating the need to confront donation actively in order to donate,"<sup>20</sup> would help solve this uneasy and unfortunate situation, and would finally "allow individuals to give effect to their true beliefs."<sup>21</sup> The routine arrangement of presumed consent is considered useful in light of the argument that "there is a repulsive feeling about donating one's organs."<sup>22</sup> People might find it difficult to agree to donate their organs for a number of reasons, including the "unimaginable condition of death" and the metaphysical "conviction of our immortality."<sup>23</sup> The argument is that because fear, taboo, and superstition surround death and bodily alteration of cadavers, we should avoid *asking* the disconcerting question of donation. Organ retrieval could then occur in a more efficacious way, without confronting the psychological blocks of individuals. It is also argued that a policy of presumed consent would erode this particular social taboo.<sup>24</sup>

Several things can be said at this point. First, calling certain beliefs about death "taboo and superstition" can be an act of contempt. It associates belief with an irrational, dark, and deviant universe. Some beliefs about death will not be easy to grasp for anyone irreligious or secular, be they nurses, physicians, bioethicists or

18. Maxwell J. Mehlman, *Presumed Consent to Organ Donation: A Reevaluation*, 1 HEALTH MATRIX 31, 46 (1991).

19. *Id.* Mehlman cites the works of Theodore Silver, who writes "[t]hat seventy-five percent of the populace should say 'yea' to organ donation from an armchair, while eighty-three percent say 'nay' from the deathbed, suggests that most people believe they should donate their organs but cannot bring themselves to do so." Theodore Silver, *The Case for a Post-Mortem Organ Draft and a Proposed Model Organ Draft Act*, 68 B.U. L. REV. 681, 697 (1988).

20. Mehlman, *supra* note 18, at 44; see also L.G. Futterman, *Presumed Consent: The Solution to the Critical Donor Shortage?*, in THE ETHICS OF ORGAN TRANSPLANTS: THE CURRENT DEBATE 161 (A. Caplan & D.H. Coelho eds., 1998).

21. Mehlman, *supra* note 18, at 44.

22. Donald R. McNeil, *The Constitutionality of "Presumed Consent" for Organ Donation*, 9 HAMLIN J. PUB. L. & POL'Y 343 (1988-89).

23. *Id.* at 359 (quoting Sigmund Freud, *Our Attitudes Towards Death*, in COLLECTED LEGAL PAPERS 304 (1925)). In a piece written in 1970, Jess Durkeminier, one of the initiators of presumed consent theory, argued that most people are unlikely to think seriously about their own death to prompt them to take even the easiest action, like making their wishes clear regarding organ donation. See Durkeminier, *supra* note 3.

24. McNeil, *supra* note 22, at 360.

lawyers. While there are taboos and superstitions about death, not all beliefs are so reducible. In fact, investigations of belief systems about death, and whether avoiding the taboos is more appropriate than facing them, are not addressed anywhere by proponents of the campaign to erode social taboos.<sup>25</sup> In addition, the assumption that many people want to donate, but are incapable of making their wishes come true is also colored by a dubious paternalism. It implies that in the area of organ procurement, some potential suppliers cannot assure their own well being, and that it is better to act on their behalf precisely by presuming their consent. The idea of "protecting people from themselves" by not disturbing them with serious issues colonizes behaviors with a paternalistic approach. Again, those arguing in favor of presumed consent do not discuss this problem.

Leaving aside the arguable issue of psychological barriers to organ donation, there are external elements that could prevent donation. Would-be donors may face social or religious pressure preventing donations. In this situation, paternalism may be useful. Presumed consent, as a default rule, might assist these individuals in the realization of their wishes despite external pressure.<sup>26</sup>

Nevertheless, there is a general sense of unease towards paternalism in current bioethical literature, especially in the feminist bioethical theory.<sup>27</sup> History teaches that both paternalism and beneficence, or paternalism alone, have been selectively applied towards historically oppressed groups like women, disabled people, ethnic minorities and the poor. Medical and political establishments often perceived these groups as *inherently* vulnerable and in need of special protection or even admonishment in order to properly look out for themselves. The relationship between presumed consent for donating organs and paternalism has a particular character. Presumed consent is portrayed as a practice based on beneficence,

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25. Since the 1970s, as exemplified in the lives of women like Karen Quinlan in the Unites States, Nancy B. and Sue Rodriguez in Canada, and the writing of Elizabeth Kubler-Ross, society's attitude towards death and dying may have changed enough so that today, people can actually think about the eventuality of death and also about organ donation. Therefore, this argument may be somewhat out-of-date.

26. These cases relate, among other things, to issues of internal minorities, which will be elaborated on later.

27. See SUSAN SHERWIN, *NO LONGER PATIENT: FEMINIST ETHICS AND HEALTH CARE* (1992); see also LAURA M. PURDY, *REPRODUCING PERSONS: ISSUES IN FEMINIST BIOETHICS* (1996); see also Rosemarie Tong, *Feminist Approaches to Bioethics*, in *FEMINISM & BIOETHICS. BEYOND REPRODUCTION* (Susan M. Wolf ed., 1996) [hereinafter *FEMINISM & BIOETHICS*].



which avoids the harm of asking people to make hard choices. Yet this point is fraught with the belief that individuals, especially in grieving families, are too fragile to deal with important, controversial and delicate matters. Perhaps a young and poor Aboriginal man can be spared the tough issues? And this unemployed, intoxicated hysterical white woman: why harass her with this dilemma when she is already so stressed?

These images capture the paternalism of presumed consent theory. Presumed consent rationalizes and justifies paternalism on the basis of beneficence towards those who should give organs. Applying the beneficence argument to those who fear death requires presumptions that are similarly fraught with paternalistic and contemptuous problems.

### *B. Implementing Presumed Consent*

Presumed consent policy was first suggested by Jess Durkeminier and David Sanders in an issue of the *New England Journal of Medicine* at a time when transplantation techniques were being developed.<sup>28</sup> The authors suggested a shift from the classical standard of informed consent: their proposal required that in post-mortem organ donation, consent be the default. The objection to consent, that is, the refusal to donate, would be the element that had to be positively demonstrated.<sup>29</sup> Presumed consent is at the very least a transformation of the method of soliciting organ donations. The theory can also be understood as a radical reversal of the narrative of organ transplantation which is based on will, desire, or at least consent, to donate one's organs. Instead of asking "do you want to give your organs after death?" and expressing that "we strongly encourage you to donate your organs after death," the discourse shifts. Now it is "we will take your organs, unless you intervene to prevent us from doing so." Durkeminier and Sanders were pioneers in this area and expressed very clearly the systematic reversal of language that would take place under a presumed consent policy. They took a rationalist's approach, and seemed to believe that modifying people's actions and thought processes were a mechanical procedure. A reader

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28. See Jesse Durkeminier & David Sanders Jr., *Organ Transplantation: A Proposal for Routine Salvaging of Cadaver Organs*, 279 *NEW ENG. J. MED.* 413 (1968); see also Durkeminier, *supra* note 3.

29. See Durkeminier, *supra* note 3; see also W.N. Gerson, *Refining the Law of Organ Donation: Lessons from the French Law of Presumed Consent*, 19 *N.Y.U. J. INT'L L. & POL.* 1013 (1987).

cannot help but envision operating machines, or playing with numbers:

At present the surgeon is told: 'You may not remove cadaver organs to save the life of a living person unless you have obtained consent from the deceased or his next of kin.' He ought to be told: 'You may remove cadaver organs to save the life of a living person unless the deceased notified you that he objected or the next of kin objects.'<sup>30</sup>

But the method of Durkeminier and Sanders may backfire. It has been argued that the resulting dissonance between the powerful "gift narrative" of old and the rational policy of "implicit mandatory supply" generated by presumed consent may paralyze the individual. The result could be that the individual will not donate organs.<sup>31</sup>

The implementation of presumed consent legislation has been uneven. It is acknowledged that there are several types of presumed consent laws, differing in their regulation of how "presumption" is made. The laws also differ in their approach to the wishes of the deceased's family.

Presumed consent legislation provisions from Austria, Brazil, France, and the United States illustrate the diversity of presumed consent legislation. These four jurisdictions provide examples from a strict approach to presumed consent to a presumption that leaves room for objections. Presumed consent in one jurisdiction includes donation of all solid organs, while in another jurisdiction, presumed consent is for the donation of eye corneas solely.

### 1. Austria

Austria has a "strict" presumed consent system. Austria's *Hospital Law* states that "[i]t shall be permissible to remove organs . . . from deceased persons"<sup>32</sup> for the purpose of transplantation, and that "[s]uch removal shall be prohibited if the physicians are in possession of a declaration in which the deceased person, or prior to his death, his legal representative, has expressly refused his consent to organ donation."<sup>33</sup> In order to avoid the

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30. See Daniel J. Crothers & Catherine G. Uglem, *A Proposal for a Presumed Consent Organ Donation Policy in North Dakota*, 68 N.D. L. REV. 637 n.74 (1992).

31. See D.K. Martin & E. Meslin, *The Give and Take in Organ Procurement*, 19 J. MED. & PHIL. 61 (1994).

32. *Federal Law of 1 June 1982* (Serial No. 273), ch. 7, § 62a (1), amended to the *Hospital Law*, No. 113, reprinted in LEGISLATIVE RESPONSES TO ORGAN TRANSPLANTATION 132 (1994) [hereinafter LEGISLATIVE RESPONSES].

33. *Id.*

retrieval of organs, the individual not only has to indicate his or her refusal, but this refusal has to be in the physician's possession at the relevant hour. Determining consent for post-mortem organ transplantation takes place in stressful circumstances, often, in an emergency setting. It is possible that the consent document will not be in the physician's possession, but rather, with the family, or at the site of the deadly accident. In cases like car accidents, gunshots, etc., the consent or refusal of the donor might as well be in the coroner's possession. Under these circumstances, Austrian law does not require the physician to seek out a document that would indicate a refusal to donate. Moreover, the legislation does not give the family of the deceased a say in the donation question.

## 2. Brazil

Brazil had a short-lived "strict" presumed consent policy. From 1997 to 1998, the *Presumed Organ Donor Law*<sup>34</sup> mandated that "[u]nless manifestation of will to the contrary, in the scope of this Law, it is presumed that authorization is given for the donation of tissues, organs and human body parts, for the purpose of transplantation or treatment of diseases."<sup>35</sup> To be excluded from the pool of donors, the person had to have the expression "non-donor of organs and tissues" engraved in an indelible and inviolable manner on her identification document or driving license.<sup>36</sup> Due to a major public outcry and serious criticism from the part of medical associations, the legislation was abolished a year after its enactment.<sup>37</sup>

## 3. France

The relevant provision of the French *Loi de Cavaillet* (1976) reads simply: "Organs may be removed for therapeutic or scientific purposes from cadavers of persons who have not, during their lifetime, indicated their refusal to permit such a procedure."<sup>38</sup> The second

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34. Decreto No. 9.434, de 4 de fevereiro de 1997, D.O.U de 1997 (repealed 1998). See Everton Bailey, *Should the State Have Rights to Your Organs? Dissecting Brazil's Mandatory Organ Donation Law*, 30 U. MIAMI INTER-AM. L. REV. 707 (1999) (For a commentary of the legislative history of the *Presumed Organ Donor Law*).

35. Decreto No. 9.434, *supra* note 34, art. 4.

36. Bailey, *supra* note 34, at 726 n.2 (quoting Decreto No. 9.434, ch. II, art. 4, § 1).

37. Claudio Csillag, *Brazil Abolishes "Presumed Consent" in Organ Donation*, 352 THE LANCET 1367 (1998), available at 1998 WL 14105861.

38. Law No. 76-1181 of December 22, 1976, on the removal of organs, § 2, reprinted in LEGISLATIVE RESPONSES, *supra* note 32, at 200; see also J. Y. Nau, *Chaque Français pourra refuser dès 1996 le don post-mortem*, LE MONDE, 20 June 1995.

paragraph of the provision makes an exception for the cadaver of a minor or of an incompetent individual, in which case the organs may be removed only with the authorization of the individual's legal representative. It is evident by reading this exception for minors and incompetent persons that dissent from the deceased's family members have no impact in regular circumstances. However, in practice, France does have a 'soft' presumed consent system because health care providers do not follow the presumed consent law and protocols.<sup>39</sup> The majority of providers have tended to stay loyal to informed consent standards in respect to the policies and practice of post-mortem organ donation; since the enactment of the presumed consent law, their practice has changed only slightly. Interestingly, the health care provider did not *assume* or *presume consent*, but would *search for objections to consent*. In terms of time and energy, the search for evidence that the individual did not consent is in effect, a search for consent. The standards and the actions of the medics are the same; the only exception being that what is sought is *refusal*<sup>40</sup> instead of *agreement*<sup>41</sup> to organ donation. The reason the system "shifted the focus from seeking consent to seeking objections"<sup>42</sup> was to allay doctors' fears<sup>43</sup> of taking organs when there might be an objection (whether from the deceased herself or from her next-of-kin) of which they were unaware.<sup>44</sup> This feature, specific to the medical context in France, softens their presumed consent rule.

#### 4. United States of America

Statutes dealing with presumed consent in the United States attempt to overcome the notion of "consent as a barrier problem."<sup>45</sup> Thus, an underlying philosophy of the statutes is that consent is a

39. See Gerson, *supra* note 29.

40. Or absence of consent.

41. Or consent.

42. M.O.R.E. PROGRAM OF ONTARIO, ORGAN PROCUREMENT STRATEGIES. A REVIEW OF ETHICAL ISSUES AND CHALLENGES 22 (1994) [hereinafter M.O.R.E. REPORT].

43. It may be the fear of hurting a mourning family, the fear of being stigmatized by the medical or social opinion, the fear of doing something morally wrong, or the fear of facing a lawsuit. Empirical support and practical justifications for these fears will be provided later in this section.

44. P. DE CRUZ, COMPARATIVE HEALTH CARE LAW 558 (2001).

45. Karen Clarke, *The Washington Hospital Center Example: A Hospital's Guide to Implementing the Rapid Organ Recovery Program*, 16 J. CONTEMP. HEALTH L. & POL'Y 501, 510 (2000); see Goodwin, *supra* note 5.

problematic obstacle to progress.<sup>46</sup> American presumed consent laws vary greatly, operating at both a strict in some jurisdictions and a softer level in others. Called "legislative consent," the strict version was first enacted in the state of Maryland.<sup>47</sup> Subsequently, twenty-eight states have passed presumed consent laws,<sup>48</sup> though presumed consent is currently practiced in only nine states.<sup>49</sup> Legislative consent provisions are included in the regulatory framework of medical autopsies, and target specific parts of the body, such as the cornea or pituitary glands.<sup>50</sup> As of July 2002, the *Maryland Estates and Trusts Code* allows the medical examiner to remove organs if "[n]o objection by the next of kin is known by the medical examiner" and if "[n]o religious objection made by the decedent before death is

46. Erik S. Jaffe, Note, *She's Got Bette Davis[s] Eyes: Assessing The Nonconsensual Removal of Cadaver Organs under the Takings and Due Process Clauses*, 90 COLUM. L. REV. 528 (1990).

47. MD. CODE ANN., EST. & TRUSTS § 4.509.1 (1998) reads in relevant part:

(a) In any case where a patient is in need of corneal tissue for a transplant, the Chief Medical Examiner, the deputy chief medical examiner, or an assistant medical examiner shall provide the cornea upon the request of the Medical Eye Bank of Maryland, Incorporated, subject to the provisions of subsection (b) of this section, and under the following conditions:

- (1) The medical examiner has charge of a decedent who may provide a suitable cornea for transplant or research;
- (2) An autopsy will be required;
- (3) No objection by the next of kin is known by the medical examiner;
- (4) No religious objection made by the decedent before death is known by the medical examiner; and
- (5) Removal of the cornea for transplant will not interfere with the subsequent course of an investigation or autopsy or alter the post-mortem facial appearance.

....

(c) [Liability of Medical Examiner] The Chief Medical Examiner, the deputy chief medical examiner, an assistant medical examiner, the Medical Eye Bank of Maryland, Incorporated, or the Lions of District 22-C Eye Bank and Research Foundation, Incorporated, are not liable for civil action if the next of kin subsequently contends that authorization of that kin was required.

*Id.*

48. See Goodwin, *supra* note 5, at n.78 (for a list of states where the legislative consent provision was implemented).

49. *Id.* at 26. These are California, Florida, Hawaii, Kentucky, Louisiana, Maryland, Michigan, North Carolina, and Wisconsin. *Id.* at n.79.

50. *Id.*

known by the medical examiner.”<sup>51</sup> The restriction for an objection based on *religion* is an interesting feature of the Code. Another requirement is that the objection has “to be known” by the medical examiner although the *Code* does not require that the medical examiner investigate for notice of objection.

The softer version of presumed consent in the American legislation is found in the 1987 *Uniform Anatomical Gift Act* (the *Act*). Here, presumed consent can be determined by way of “reasonable effort.” The *Act* is a model, available for adoption by states. It creates statutory removal for purposes of transplantation only. A medical examiner (or other authorized person in conformity with the *Act*) is authorized to remove body parts from the deceased after the medic has exercised a “reasonable effort” to locate a refusal or contrary indication by the decedent, and to obtain consent from the next of kin to post-mortem organ procurement.<sup>52</sup> The duty for the medical examiner to make a reasonable effort rises and falls in accordance with the “useful life of the part”<sup>53</sup> to be removed.

Controversial applications of American presumed consent laws include pre-consent perfusion, which consists in injecting a cold preserving fluid into the patient’s organs (abdominal cavity and kidneys) to avoid the deterioration of organs, without first attempting to locate consent from next of kin.<sup>54</sup>

The above demonstrates a number of problems pertaining to the application of presumed consent legislation in several jurisdictions. Whether the absence of objection to procure organs is even relevant, whether it has to be self-evident, or whether it has to be sought, looked at, or profoundly searched for by health care providers until an actual objection arises, is unclear in some jurisdictions. Second, there is no consensus respecting whose silence is relevant: the patient, the next-of-kin, or both.<sup>55</sup> Finally, the fact that some presumed consent

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51. MD. CODE ANN., EST. & TRUSTS § 4.509.1(a)(3)(4) (1998).

52. UNIF. ANATOMICAL GIFT ACT § 4 (National Conference of Commissioners on Uniform State Laws 1987).

53. *Id.* at § 4, cmt.

54. Mark Anderson, *The Future of Organ Transplantation: From Where Will New Donors Come, To Whom Will Their Organs Go?*, 5 HEALTH MATRIX 249, 310 n.69 (1995); CRUZ, *supra* note 44, at 581.

55. The issue of family veto over an individual decision over post-mortem organ procurement is beyond the scope of this paper. I discuss it in Marie-Andree Jacob, *Consent, Conversation, and the Regulation of Post-mortem Organ Procurement in a Multicultural Canada* (unpublished LL.M. thesis) (on file with author).

laws also acknowledge the validity of informed consent to organ donation adds to the confusion.

It has been noted that often doctors fail to observe presumed consent laws.<sup>56</sup> Many of them might simply not know the law. Others might be motivated by fears of legal liability or by concern for the grieving family.<sup>57</sup> Additionally, why do medics contravene these laws? It appears that sometimes, a health care provider does not act in accordance with a presumed consent scheme. Not following the scheme derives the following benefits: the burden of asking for consent is avoided *per se* (this is an efficient advantage); the life of another patient could be saved following a doctor's rapid, unchallenged action with the body of a recently deceased person unable to object to donation; and in some cases, these efficiency-oriented presumptions of consent receive legal endorsement. The reluctance of doctors to follow presumed consent practices, in spite of these advantages, reveals some doctors' commitment to the threshold of informed consent by donors (surely there is an influence of the law as well). The *de facto*, and often purposeful, non-compliance on the part of health care providers reveals at the very least a serious flaw in the application of presumed consent laws.

### *C. Efficient Implementation and the Need for Assessment*

Despite the critiques, a presumed consent policy should be considered. The question arises of whether efficient and sustainable applications of presumed consent, if unchallenged in courts, ground presumed consent as an ethically sound health policy. It appears that when presumed consent is applied strictly and consistently, it can "work"; that is, the result can be a substantive increase in the available amount of transplantable organs, but at what social cost.<sup>58</sup> Issues about efficiency and utilitarianism enter the bioethical analysis. If presumed consent increases rates of donation and saves lives, is it sufficiently successful to override other ethical considerations? Furthermore, assuming it would not cause controversy in the population and front-page stories in the media, and would not be challenged in court by litigants, could it justify its admission as a public health policy?

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56. Interview with Jacquie Lang, Transplant Coordinator at the Trillium Gift of Life Network (formerly M.O.R.E. Program of Ontario, and then Organ Donation Ontario) (Feb. 14, 1999 and Nov. 16, 1999); see also M.O.R.E. REPORT, *supra* note 42.

57. See Lang, *supra* note 56.

58. See Goodwin, *supra* note 5.

It is awkward to challenge a policy that attempts to save lives and increase quality of life. The protection of life is an overarching priority in most societies. It follows that the increase of the supply of transplantable organs might be the most urgent factor for consideration in the creation of a *good* organ procurement policy. The problem is that the protection of lives, and of quality of life, can hardly be pursued ethically if it is pursued without regard for social oppression and disempowerment. Therefore, policies of procurement ought to acknowledge that the supply of organs is not the only issue to consider. Other considerations include: how to obtain the supply; the source of the supply; and to whom will the supply be directed; and whose lives and quality of life will be improved. These are issues that an organ procurement policy must take into consideration.

For example, since the purpose of presumed consent policy is to encourage the communitarian principle of sharing of social goods, organs, amongst *all*,<sup>59</sup> based on their needs, the policy must truly benefit *all*. Furthermore, if we are to enact a policy of presumed consent to encourage altruism on the basis that we should all contribute to the social contract, as full members of the contract, then contributions must be made in fairness for all members. It would be unacceptable if certain members contributed over-proportionally, without benefiting from the contract. In this respect, historical and contemporary inequalities between the participants of the social contract should be considered.<sup>60</sup>

Alongside procurement matters, issues of allocation of donated organs will arise when contemplating fairness. These issues are beyond the focus of this paper. Rather, this article considers whether presumed consent, as a strategy of increasing the supply of transplantable organs, imposes the onus of the enterprise

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59. Obviously, "all" is said normatively. Canada, for example, has in fact made a commitment to provide medical services for all, through a predominantly publicly financed, privately delivered health care system known to Canadians as "Medicare." The system aims to be universal and comprehensive. Canada Health Act, R.S.C., ch. C-6, §§ 9-10 (1985) (Can.).

60. See Goodwin, *supra* note 5. Carole Pateman wrote about the fallacious nature of the social contract, in which supposedly, all members participate by giving up and benefiting equally, and on how such a social contract is based on a brotherhood hermetic to women's participation as full members of the contract. See CAROLE PATEMAN, *THE SEXUAL CONTRACT* (1988). A "racial contract," by denying personhood to certain men and by restricting its terms to whites only, is also a reality that has little to do with the liberal idea of the social contract. See CHARLES W. MILLS, *THE RACIAL CONTRACT* (1997); see also Anthony Farley, *The Black Body as A Fetish Object*, 76 OR. L. REV. 457 (1997).



disproportionately on the most fragile members of society. Nevertheless, if this enterprise is assessed with an equality paradigm, the issue of procurement cannot be fully disconnected from allocation problems.

In unequal societies, it is likely the organ shortage will be borne by the disadvantaged, and the available supply will be channeled towards the advantaged. Therefore, an overall increase in the supply of organs might benefit the less privileged members of society in the end by easing the pressure specifically placed on their community. The test would be whether there are benefits to the underprivileged in allocation, when weighed against the procurement statistics of this socioeconomic stratum. Organ transplantation is a sophisticated and expensive procedure, and its performance involves many costs for the recipients, even those in a public universal health system; many of the related costs will remain uncovered by private or government-sponsored health plans (e.g. anti-rejection medications). These factors might limit access to organ transplantation for the poor and minority groups.

The primary focus of this paper is an assessment of the implications of presumed consent as a procurement strategy. Since procurement takes place in the general context of social inequality, the issue of procurement can also be assessed on its own, that is, without the reference to allocation. Two theories of guidance in this inquiry include: deliberative ethics and its constructive criticism, and sensitivity to cultural difference in health issues.

### III. INPUTS FROM DELIBERATIVE ETHICS AND SENSITIVITY TO CULTURAL DIFFERENCE

#### *A. Deliberative Ethics Framework*

If a presumed consent policy applied to post-mortem organ removal, there might be a lack of voluntary responses. This phenomenon would disempower people, rendering them passive in the face of social change. This is precisely what supporters of deliberative ethics fear.

Proponents of deliberative ethics, including many feminists<sup>61</sup> and political philosopher Jürgen Habermas,<sup>62</sup> have focused on

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61. See Tong, *supra* note 27; see also Janet Farrell Smith, *Communicative Ethics in Medicine: The Physician-Patient Relationship*, in FEMINISM AND BIOETHICS, *supra* note 27, at 184; Therese Murphy, *Health Confidentiality in the Age of Talk*, in FEMINIST PERSPECTIVES ON HEALTH CARE LAW 155 (Sally Sheldon & Michael Thomson eds., 1998).

communication itself as an ethical framework. Participating in ethical deliberations results in empowerment and self-affirmation.

An ethics of communication, also known as deliberative ethics, asserts that awareness, reflection and response by individuals on social issues are crucial. Its basic underlying premise is that when agents face disagreements, discussion should take place until a mutually acceptable resolution is found. Specifically in the legal context, it is believed that deliberative ethics should be mobilized through connection between the participation in the discussion (in making the law) and a correlative personal involvement (in following the law). In other words, because they contribute in establishing what the law will be, citizens will comply with it afterward.<sup>63</sup> Communication, here, is not simply a procedural step towards a specific goal, but a ground from which ethical values can emerge. Human speech is a form of action *per se*, which allows for exploration of new norms and policies. Deliberations, discussions and critique become the sources and essential *components* of the validation of principles. Eventually, from the better reasoned and better articulated arguments, admitted ethical principles will emerge.

This ethical process, however, does not necessarily lead to consensus or agreement. But if no consensus is achieved, then what is the point of a deliberative ethics? Will it keep citizens paralyzed by other's standpoints and oppositions, or chaotically trying to convince one another? For instance, with respect to consent to post-mortem organ removal, it is possible that policy-makers, lawyers, donors, donor families, recipients, their families, nurses, physicians and hospital coordinators may never reach a workable consensus. For this situation Janet Farrell Smith establishes a distinction between consensus and "mutual understanding":

Rather than discussion aimed at persuasion, pressure, or manipulation of the hearer to achieve the speaker's ends, the goal is mutual comprehension and reasonable assessment. The fundamental ethical points lie in two subjects reaching reciprocal

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62. See JURGEN HABERMAS, *COMMUNICATION AND THE EVOLUTION OF SOCIETY*, (Thomas McCarthy trans., 1987); see also DAVID M. RASMUSSEN, *READING HABERMAS* (1990); see also STEPHEN K. WHITE, *THE RECENT WORK OF JURGEN HABERMAS: REASON, JUSTICE, AND MODERNITY* (1988).

63. See Robert J. Lukens, *Discoursing on Democracy & the Law - A Deconstructive Analysis*, 70 TEMP. L. REV. 587 (1997); see also Bjarne Melkevik, *Transformation du droit: le point de vue du modèle communicationnel*, in *AUX FRONTIÈRES DU JURIDIQUE : ÉTUDES INTERDISCIPLINAIRES SUR LES TRANSFORMATIONS DU DROIT* (Jean-Guy Belley & Pierre Issalys eds., 1993).

understanding while holding full respect for each other's reasoning process, reasons, feelings, and authentic noncoerced participation.<sup>64</sup>

Yet, query whether all citizens are equal, uncoerced participants in public forums and private discussions. In a similar manner, in the context of health care, are patients and their physicians involved in a *reciprocal* exchange of information, reasoning and doubting? In the specific context of organ retrieval, where certain actors have technical knowledge, familiarity with very sophisticated procedures, and more power than others, is a cooperative reciprocity genuinely possible?

Consider further that Farrell Smith, building on Habermas, raises the important distinction between a strategic transmission of information by speakers to listeners, and a cooperative communicative action where both actors feed each other. Instead of merely delivering knowledge, communicative action is a process of interaction in which agents *understand* each other, and even, as summed up by Rosemarie Tong, "conclude their unique stories satisfactorily."<sup>65</sup>

But the question as to *how* agents who are *unequal* can feed each other *mutually* remains unsolved. Farrell Smith and Tong reject Habermas' law of the "force of the better argument," which they find reductive of communication (something equivalent to an argumentation to achieve consensus). Rather than a model aiming for agreement, they prefer a model acknowledging differences that aims to reduce and dissolve them into a mutual understanding. Their model for interactive deliberation emphasizes identification with others, but might obscure barriers. In fact, mutual understanding implies pre-existing cognitive reciprocity. Genuine cooperative communicative efforts imply mutual respect at the moral level. Yet both are generally absent within systematically unequal relations such as patient and health care provider relations; so agents in this area can hardly reach satisfactory mutual arrangements and understandings. Moreover, it is likely that in health care settings,

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64. Smith, *supra* note 61, at 186.

65. See Tong, *supra* note 27, at 70. Tong's framework for bioethical decision-making is conversationalism. Tong defines conversationalism as the belief that the ultimate aim or function of bioethical decision making is "to reveal to people the moral content and the consequences of their family traditions, psychological characteristics, spiritual resources,<sup>65</sup> socioeconomic status, personal experiences, and religious beliefs." *Id.*

social power difference prevents people from negotiating on an equal foot to begin with.<sup>66</sup>

The asymmetry results not only from economical and political inequalities, but also derives from a socially constructed, internalized sense of having something to say, and from the valorization of certain types or forms of expression over others. Deliberation is not neutral; it is based on shared assumptions about speech itself. How to discuss, what language to employ, and how to express disagreements can come into play. For example, in scientific and medical settings, refused consent by marginal patients such as poor women of color, is often reduced to an individual opposition or self-defensiveness, an irrational expression of anger, stubbornness, or selfishness. Consent is rarely recognized as a legitimate site of power. It is rarely acknowledged, let alone encouraged, as a worthwhile, distinct expression informed by one's gender, class, race, or religion.

Generally, decisions to deviate from the norm, whether they be of reasonable usages, unwritten rules, or default rules, will raise suspicion.<sup>67</sup> Thus, opting-out of presumed consent might be regarded as unreasonable. The expression of dissent might also come with other costs, for example, losing the little mutual trust and cooperation remaining in a relationship with an institution or its representative (the state, a hospital, a physician), or being pushed even further to the margins.

In this arena, where communication is fraught with difficulties, and where agreements or even mutual understandings might not occur, there is little room for presumptions of consent. Rather, there is room for listening. Yet, presumed consent laws are goal-oriented and encourage silence as the mode of "participation" or "self-expression." In the case of organ procurement, discussing consent to post-mortem donation makes more sense than avoiding it. Asking for consent is preferable to presuming it; and listening to its expression rather than picturing it, is the only option for genuine communication. The real possibility of genuine deliberation is still a long way ahead of us. Nevertheless, this approach would be a bit closer to empowerment, agency and responsibility, and could create a "discrete site of

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66. IRIS MARION YOUNG, *INTERSECTING VOICES: DILEMMAS OF GENDER, POLITICAL PHILOSOPHY, AND POLICY* 63 (1997). See also Murphy, *supra* note 61.

67. See Eyal Zamir, *The Inverted Hierarchy of Contract Interpretation and Supplementation*, 97 COLUM. L. REV. 1710 (1997).

rebellion"<sup>68</sup> against submission and silence in the area of post-mortem organ procurement.

Two final things should be mentioned about deliberative ethics. First, the shortage of organs has been construed as a crisis to be solved through crisis management. Yet communicative action in making bioethical choices is not counter-efficient *per se* to the goal of increasing organ supply. Second, and more importantly, organ procurement is not strictly a crisis to be solved. It is a social issue, an "opportunity" for individuals to empower themselves and to become responsible by making their own choices (to donate or not). This long-term goal should not be eliminated in order to satisfy urgent, but short-term, public needs.

### *B. Input from a Multicultural Sensitivity*

What is the place of cultural difference as a variable in health policy assessment? How can adequate comment about groups and communities be made, in particular about "ethnicity" and "culture" in the context of health care? There are definite risks in using these terms when constructing an argument.<sup>69</sup>

By drawing attention to ethnic differences, one runs the risk of problematising ethnicity rather than focusing on racism.<sup>70</sup> Oppressive or ambient racism can be obscured by an emphasis on culture, ethnicity, and on their distinctive, "exotic"<sup>71</sup> features. A second concern over the careless usage of the words ethnicity and culture is that they often oversimplify categories. Any categorization, even if subtle, can never perfectly represent the reality of humankind.<sup>72</sup> Most importantly, ethnicity is not fixed: "Ethnicity is a shifting category which can change over time, whether defined by individuals

68. I owe this terse and powerful expression to Khiara M. Bridges, from her piece about the risks of further alienating Black Female America though the alienability of aborted fetuses. Khiara M. Bridges, Note, *On the Commodification of the Black Female Body: The Critical Implications of the Alienability of Fetal Tissue*, 102 COLUM. L. REV. 123, 138 (2002).

69. See RESEARCHING CULTURAL DIFFERENCES IN HEALTH (David Kelleher & Sheila Hillier eds., 1996) [hereinafter CULTURAL DIFFERENCES].

70. *Id.*; see also RACE AND HEALTH IN CONTEMPORARY BRITAIN (Waqar I. U. Ahmad ed., 1993); see also Waqar I. U. Ahmad, *The Trouble with Culture*, in CULTURAL DIFFERENCES, *supra* note 69, at 190; see also Avtar Brah, *Difference, Diversity and Differentiation*, in RACE, CULTURE AND DIFFERENCE 126 (James Donald & Ali Rattansi eds., 1992).

71. See Jenny Donovan, WE DON'T BUY SICKNESS. IT JUST COMES: HEALTH, ILLNESS AND HEALTH CARE IN THE LIVES OF BLACK PEOPLE IN LONDON (1986).

72. *Id.* at 4.

themselves or by others. Therefore, we must expect definitions to change and the relevance of some categories to increase or disappear."<sup>73</sup>

To quote Chetan Batt : "[s]ocial difference' is continually remade and is a contingent, incomplete and aggregate process rather than a pre-existing edifice."<sup>74</sup> Batt also points out that differentiation is not exterior to an already defined group identity that knows its content, boundaries, and place in relation to other group identities. Instead, differentiation is "radically interior and disruptive of those group identities. Indeed, a primary function of identity is precisely to manage and contain the differentiation which constantly threatens it."<sup>75</sup>

Therefore, if a multicultural state considers the shared, culturally specific values of minority groups, it should be careful not to construct groups as homogeneous cells. Rather, it should recognize their intra-ethnic difference.<sup>76</sup> Gender, social class, age, religion, level of education and area of origin in the home country (i.e. rural or urban) mark critical differences within an immigrant group. These differences can disrupt anything so-called "characteristic" about the group's identity.<sup>77</sup> However, the practice in health care settings does not reflect this reality. Some members of minority groups experience their contact with health professionals as "stereotyping," for example, behaving towards them as if all East Indians are the same.<sup>78</sup> Again, there are also risks inherent in putting emphasis on "differences," because focusing on difference underscores the stigma of deviance.<sup>79</sup> Sherene Razack provides a fair account of the dangers of this type of attitude towards cultural difference. She states that too often, the

73. *Id.*

74. Chetan Batt, *New Foundations: Contingency, Indeterminacy and Black Translocality*, in, *THE LESSER EVIL AND THE GREATER GOOD: THE THEORY AND POLITICS OF SOCIAL DIVERSITY* 138, 161 (Jeffrey Weeks ed., 1994) [hereinafter *THE LESSER EVIL*].

75. *Id.*

76. Shasi Assanand et al., *The South Asians*, in *CROSS-CULTURAL CARING: A HANDBOOK FOR HEALTH PROFESSIONALS IN WESTERN CANADA* 246 (Nancy Waxler-Morison et al. eds., 1990); Donald P. Irish et al., *Conclusions to ETHNIC VARIATIONS IN DYING, DEATH, AND GRIEF: DIVERSITY IN UNIVERSALITY* 182 (Donald P. Irish et al. eds., 1993) [hereinafter *ETHNIC VARIATIONS*].

77. Nancy Waxler-Morison, *Introduction to ETHNIC VARIATIONS*, *supra* note 76, at 8.

78. *Id.*

79. See Joan W. Scott, *Deconstructing Equality-versus-Difference: Or, The Uses of Poststructuralist Theory for Feminism*, 14 *FEMINIST STUDIES* 33 (1988).

implementation of multicultural policies in different spheres of life can turn into "politics of rescue" and into fantasizing about helping out the exotic other. As a result, those who claim to assist oppressed groups in fact perpetuate inequalities by speaking for them, outlining superficially their features, beliefs, and behaviors, and do not offer them a genuine, empowering voice.<sup>80</sup> Hence a celebration of difference, if not accompanied with genuine recognition, further marginalizes excluded and powerless groups.<sup>81</sup> On the other hand, ignoring difference is even more dangerous. In the case of subordinated groups, it leaves in place a "faulty neutrality."<sup>82</sup> This is the "difference dilemma," as presented by Martha Minow.<sup>83</sup>

Acknowledging difference in health care bears a particular importance. The history of medicine reveals that certain bodies have repeatedly been de-valued and mistreated over the bodies of others. This created "difference." Devaluation of the body occurred in the context of scientific experiments or other motives fulfilling the public health and the public good. The eighteenth, nineteenth, and twentieth centuries are replete with medical research that abused people's bodies, especially those of women, Jews, and blacks.<sup>84</sup> Bodies

80. SHERENE H. RAZACK, *LOOKING WHITE PEOPLE IN THE EYE: GENDER, RACE AND CULTURE IN COURTROOMS AND CLASSROOMS* (1998). Razack argues:

What makes the cultural difference approach so inadequate in various pedagogical moments is not so much that it is wrong, for people in reality are diverse and do have culturally specific practices that must be taken into account, but that its emphasis on cultural diversity too often descends, in a multicultural spiral, to a superficial reading of differences that makes power relations invisible and keeps dominant cultural norms in place.

*Id.* at 9.

81. See Judith Squires, *Ordering the City: Public Spaces and Political Participation*, in *THE LESSER EVIL*, *supra* note 74, at 79.

82. See MARTHA MINOW, *MAKING ALL THE DIFFERENCE: INCLUSION, EXCLUSION, AND AMERICAN LAW* (1990).

83. *Id.* at 19.

84. See ANN G. DALLY, *WOMEN UNDER THE KNIFE: A HISTORY OF SURGERY* (1992); Rebecca Dresser, *What Bioethics can Learn from the Women's Health Movement*, in *FEMINISM & BIOETHICS*, *supra* note 27, at 144; see also Paul Starr, *THE SOCIAL TRANSFORMATION OF AMERICAN MEDICINE* (1982); see also DAVID J. ROTHMAN, *STRANGERS AT THE BEDSIDE: A HISTORY OF HOW LAW AND BIOETHICS TRANSFORMED MEDICAL DECISION MAKING* (1991); see also Allan M. Brandt, *Racism and Research: The Tuskegee Syphilis Experiment*, in *TUSKEGEE TRUTHS: RETHINKING THE TUSKEGEE SYPHILIS STUDY 15* (Susan M. Reverby ed., 2000); see also Patricia A. King, *Race, Justice, and Research*, in *BEYOND CONSENT: SEEKING JUSTICE IN RESEARCH 88* (Jeffery P. Kahn et al. eds., 1998); see also Farley, *supra* note 60; see also Goodwin, *supra* note 5.

of the poor and of people with disabilities have also been enthusiastically subjected to research that consumed accessible, interesting raw material. In the context of organ procurement policy-making, these historical inequalities must be taken into account. They have a direct influence on the willingness of certain groups to donate organs.<sup>85</sup>

In health-related matters, an example of genuine recognition is to admit that difference, in itself, can become a source of confronting knowledge for policy-makers. For example, differences in religions can provide novel grounds to test the conceptual claims, premises and limits of knowledge. While admittedly a sign of cultural difference, religion has been deliberately excluded in consideration of the impetus behind people's ethics and vision of the good.<sup>86</sup> Relegating religion as a *sign* of cultural difference, or a mere symptom expressing itself with rites, has unjustly superficialized the religious difference, and is ignorant of religion's part in the life of the subject. Put fully, religion is "a cultural instrument rather than a mark of cultural difference."<sup>87</sup> It can be behind a person's ethics; it can also be a motor of cultural production at the social level. Religion profoundly shapes world-views and conceptions about health, quality of life, death, or bodily integrity.

Religious discourse is a source of beliefs and values that can ground people's support or refusal to donate one's organs after death. Certain religious tenets focus on the sacredness of the body and the preservation of life. Jewish law, for example, requires "that Jews take steps to preserve their life and health, even when secular law and medical practice might have determined death."<sup>88</sup> As these beliefs might inhibit some Jews to voluntarily participate in post-mortem

85. See Goodwin, *supra* note 5.

86. Gayatri Chakravorty Spivak, *The Politics of Translation*, in *DESTABILIZING THEORY: CONTEMPORARY FEMINIST DEBATES* 177, 192 (Michele Barrett & Anne Phillips eds., 1992).

87. *Id.* Further, according to Gayatri Spivak, religion might be an important key to better understand marginal voices; since "given the connection between imperialism and secularism, there is almost no way of getting to alternative general voices except through religion." *Id.* See also Nancy Frankenberg, *Philosophy of Religion in Different Voices*, in *PHILOSOPHY IN A FEMINIST VOICE* 173 (Janet A. Kourany ed., 1998).

88. Goodwin, *supra* note 5, at 33 (quoting Elliot N. Dorff, *Choosing Life: Aspects of Judaism Affecting Organ Transplantation*, in *ORGAN TRANSPLANTATION: MEANINGS AND REALITIES* 168, 177 (Stuart J. Younger et al. eds., 1996)). See also D.W. Weiss, *Organ Transplantation, Medical Ethics, and Jewish Law*, 20 *TRANSPLANTATION PROCEEDINGS* 1071 (1988).



organ procurement, a policy presuming their consent could offend the religious observant members of this community.

Unfortunately, however, in the context of health care, "many members of cultural minorities feel that health professionals do not understand them and *assume* that they feel and believe just as others . . . do."<sup>89</sup> Further, health professionals who acknowledge "cultural difference," may not go so far as to recognize the presence of dissenting internal minorities within a culture. Efforts have to be made in the law and policy of organ collection to recognize the different *choices* with respect to cadaveric organ procurement made by citizens from different ethno-cultural and religious backgrounds, despite pressures for rapidity and ease of organ collection.

The heterogeneity of society requires attention. Institutions such as hospitals have a responsibility to concern themselves with it. They are more than just service providers. Canadian law has spoken about such institutions and about their relation to the survival of communities: "They are cultural milieus which provide individuals with the means of expressing their cultural identity, and which by extension permit them to reaffirm their cultural adherence to a community."<sup>90</sup> As mentioned earlier, the idea and empowerment of choice and deliberation by potential organ donors is more ethically sound than a policy of silence towards the question of organ donation. This norm of choice is more significant when the decision-makers, in this case, patients might be in deep disagreement with one another because of their respective cultural or religious heritage. At issue are the implications of the explicit recognition of diversity in organ procurement.

In today's pluralistic societies, consensus is difficult to obtain. Therefore, if obtained, suspicion is cast upon the actors in the so-called "consensual" result.<sup>91</sup> Deliberative ethics and multiculturalism are connected in the analysis that fosters this suspicion. The disagreements, negotiations and passions that emerge from culturally diverse groups about post-mortem organ procurement are important, especially in contrast to the homogeneous vision of organ transplantation shared in the medical community. It is interesting to consider whether, in a culturally homogeneous country like Japan, for

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89. ETHNIC VARIATIONS, *supra* note 76, at 8 (emphasis added).

90. *Lalonde v. Ontario (Commission de Restructuration des Services de Santé)*, [1995] 181 D.L.R. (4th) 266, *aff'd*, 208 D.L.R. (4th) 577.

91. See Judith Squires, *Ordering the City: Public Spaces and Political Participation*, in *THE LESSER EVIL*, *supra* note 74, at 79.

example, presumed consent could be an ethically acceptable policy. Later, this paper will elaborate on the factors that may render presumed consent problematic even in so-called homogeneous societies. Additionally, the issue of class, for example, is another characteristic ignored by exclusionary practices, demonstrated *infra*, but first, a discussion of deliberative ethics and its practice within the framework of multiculturalism.

### C. *Linking Deliberation and Multiculturalism*

Multiculturalism is tightly bound to the concept of *choice*. A certain vision of freedom of choice and of liberalism, based on a commitment to personal autonomy, and also deeply grounded in a concern with cultural membership, is elucidated by Will Kymlicka.<sup>92</sup> Kymlicka connects individual choices and culture not only because the former is dependent on the latter, but more powerfully because the making of choices influences cultural practices/societal practices, and vice-versa.<sup>93</sup> For him, meaningful individual choice is possible only if individuals deliberate, that is, have access to information and the opportunity to reflectively evaluate, freely express, and exchange thoughts. Individuals also need access to a societal culture. Group-differentiated measures, distinctive of multiculturalism, which secure and promote this access, may have a legitimate role to play in a liberal theory of justice.<sup>94</sup> Kymlicka specifies that our societal culture provides various options from which individuals can engage in deliberation and make choices. More importantly, it makes these options meaningful.<sup>95</sup>

Why don't the members of a minority culture simply integrate into the majority societal culture, leaving behind their other culture to decay and fade out? Kymlicka says that if integration is slow, the original culture is retained to serve as the primary focus of identification.<sup>96</sup> This is because it is based on simple belonging, not accomplishment.<sup>97</sup> Further, unity and consensus in the majority societal culture cannot be forced or fabricated. To quote Judith Squires:

92. See WILL KYMLICKA, *MULTICULTURAL CITIZENSHIP: A LIBERAL THEORY OF MINORITY RIGHTS* (1995); see also C. TAYLOR, *MULTICULTURALISME: DIFFERENCE ET DEMOCRATIE* (A. Gutmann ed., D-A Canal trans., 1994).

93. See KYMLICKA, *supra* note 92.

94. *Id.* at 84.

95. *Id.*

96. *Id.* at 89.

97. *Id.*

The urge to bring things into unity necessarily entails expelling some properties or entities—there is always a remainder. To put this in another way, the community is defined in opposition to that which is excluded from it . . . . Thus . . . the aspiration towards civilized cohesive communities with shared values, languages and aims, inevitably involves exclusion.<sup>98</sup>

A presumed consent policy, by *imposing* a specific culture, a culture of prolonging life, of organ transplantation, of donors and recipients and of utilitarian fragmentation of dead bodies, would presume and then assure its superiority over other cultures. It is arguable that informed consent does the same, in presuming refusal and thus imposing a framework of non-donation. The fact that there exists a right to opt-out from the presumed organ donation system is used as a counter-argument to accusations that presumed consent policies attempt to impose a culture: it is only a presumption after all. Correspondingly, one can contract-out from the informed consent system by choosing to donate. However, the comparison with presumed consent does not hold up.

Under strict presumed consent, a mere right to opt-out does not leave enough room for active and empowered decisions, as shall be further explored in Part III. Indeed, it encourages silence as the privileged mode of participation. Informed consent does not. Under the soft version of presumed consent, the authority presumes consent, and must make a qualified “reasonable effort” to verify its presumption by searching for a dissenting voice behind the silence. Still, the reasonable efforts to search and get to alternative voices are preceded by a medical criterion, that is, the priority to preserve the useful life of the organs to be harvested. Moreover, the substance of the “reasonable efforts” requirement is unclear.

Minorities remain disadvantaged in a situation of reversible presumption: the burden to opt-out is theirs, regardless of the language barriers, misunderstandings and communication problems they may encounter in health care facilities. In a multicultural society, the medical community should “view organ donation through a cultural lens, using understanding and sensitivity to each ethnic group’s cultural framework and the way in which it may influence their decision about whether to donate.”<sup>99</sup> Requests for organ

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98. Squires, *supra* note 81, at 94-95.

99. See T. Randall, *Key to Organ Donation May Be Cultural Awareness*, 265 JAMA 176 (1991); see also BASHIR QURESHI, *TRANSCULTURAL MEDICINE: DEALING WITH*

donation should be made in a manner that respects cultural difference.<sup>100</sup>

One potential critique of this turn to deliberation and to multiculturalism is the irony that encouraging debate about the issue of post-mortem organ procurement imposes standards upon *how* to address values and life-choices. Choosing deliberation as the best mode for mobilizing values and encouraging respect for multiplicity of values has its own normativity. There are communities in which it is offensive to talk about issues like death, dead bodies, and opening dead bodies. Some might prefer not to address the issues, even at the cost of losing control over treatment of the body upon death. Some might be so absolutely opposed to post-mortem organ donation that simply discussing it causes them a great deal of distress. Yet, when hospitals or organ procurement agencies do not know the decedent's wishes, they inevitably have to open communication on the matter. Yet the critique does not point out why presuming anything from these people is a more justified course of action. Presumptions, at least in the strict approach, solemnizes silence as the vehicle of decision-making. In doing so, they also systematically repress the multiplicity of voices on the issue. It is true though that the softer version of presumed consent, by requiring only a "reasonable effort" to locate objections, does not pressure those who prefer not to deliberate about this issue to reluctantly express themselves.

The next section takes a closer look at the nature of presumptions, and considers whether presumptions of consent are different from mere deductions in the way they treat choices. Following this, two paradigms for presumed consent will be presented: tacit consent and consent by inference. The supposed neutrality of the presumption mechanism will also be investigated. The inequalities prevailing of status, access to speech, and capacity to articulate consent expressly cause problems for the "neutral" understanding of presumed consent. Presumptions apply more for certain groups than for others.

#### IV. PRESUMED CONSENT: TACIT CONSENT OR CONSENT BY INFERENCE?

Tacit consent can be constructed as the mode of expression most facilitated by presumed consent. Tacit consent can be given by silence

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PATIENTS FROM DIFFERENT CULTURES (2d ed. 1994); see also RACHEL SPECTOR, CULTURAL DIVERSITY IN HEALTH AND ILLNESS (4th ed. 1996).

100. See Randall, *supra* note 99.

or absence of positive action. Yet our society does not give a voice to all. Therefore, silence or the absence of positive action does not have a unique significance, and is not necessarily deliberate. Second, silence, or absence of positive action can be considered symptoms, not substantive responses. What lies behind a silence, or a "tacit consent," is not always clear.

#### *A. Can (Tacit) Consent be Presumed?*

In *The Leviathan*, contractarian theorist Thomas Hobbes suggests that signs of contract and consent are either express or by inference.<sup>101</sup> Hobbes therefore validates tacit consent as a standard paradigm for consenting to contracts. Hobbes defines acts that *signify* consent, either tacit or express, as distinct from acts *implying* consent. An act *signifying* consent is a medium for a specific message, consent. It is a sign, a signal, a representation that expresses and transmits from one person to another the content of the message of consent. It is distinct from an act *implying* consent; the latter being more like a hint that opens the door for the deduction, the inference, and the drawing of conclusions by the observer. Acts *implying* consent are the source of John Locke's conception on tacit consent.<sup>102</sup> For Locke, consent to political and social obligations can be inferred by the observer, regardless of the potential consentor's intentions or even awareness that she or he is consenting. Locke's notion of tacit consent is hypothetical, or rather, conditional, in the sense that consent exists and binds automatically *if* it is given to good government. In this sense, Locke stresses that the quality of the government is a source for the quality of the consent towards obligations. Following his reasoning, the fact that donating cadaveric organs to others is *good* policy would *of itself* be a ground for validating people's tacit consent to make such gifts. This argument does not go on to imply that if donating cadaveric organs is good, it justifies automatic removal *regardless of people's consent*. Rather, Locke is saying that *if* such donations are good, there are grounds to *assume people's tacit consent* to do it.

Working from this basis, A. John Simmons defines consent "by inference," or Locke's tacit consent, and investigates why the conception of agreement ought to be categorized differently from

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101. See THOMAS HOBBS, *The Leviathan*, in THE ENGLISH WORKS OF THOMAS HOBBS OF MALMESBURY (Scientia Verlag 1966).

102. See JOHN LOCKE, TWO TREATISES OF GOVERNMENT (Cambridge University Press 1960).

express consent.<sup>103</sup> According to Simmons, if consent can be tacit, it is not because it has a different meaning from express consent. Calling consent tacit does not point to its lack of expression, but instead captures its special mode of expression. Tacit consent is given and expressed just like express consent. It is simply expressed by the failure to do certain things. But under what conditions can silence, or lack of action, be deemed a genuine sign of consent? According to Simmons, it should be clear to the potential consentor that consent is appropriate. Practically, this means that the potential consentor is awake and aware of what is happening. Second, acceptable means of expressing dissent must be available, and understood or made known to the potential consentor. Third, the point at which expressions of dissent are no longer acceptable must be obvious to the potential consentor. These three conditions ensure that the silence signifies tacit consent. In the sphere of political and social obligations, two other conditions are added: fourth, the means acceptable to indicate dissent must be reasonable and reasonably easily performed; fifth, the consequences of dissent cannot be extremely detrimental to the potential consentor.<sup>104</sup>

Simmons emphasizes that silence, or failure to act, can be based on a misunderstanding of the issues at stake or of the procedures to express dissent. In this case, there is a breakdown in communication among the agents, and despite appearances, the result is not tacit consent. Tacit consent is a delicate construction. Its tacit characteristics must be deliberate:

[O]nly if tacit consent is treated . . . as a deliberate undertaking can the real force of consent theory be preserved. For consent theory's account of political obligation is appealing only if consent remains a clear ground of obligation, and if the method of consent protects the individual from becoming politically bound unknowingly or against his will. And it seems clear that these essential features of a consent theory cannot be preserved if we allow that tacit consent can be given unintentionally.<sup>105</sup>

Simmons' commitment to intentional consent is critical of John Locke's interpretations of tacit consent to political and social obligations.<sup>106</sup> Simmons finds that Locke's conception of tacit consent widens the definition of consent to render it almost unrecognizable.

103. See ALAN JOHN SIMMONS, *MORAL PRINCIPLES AND POLITICAL OBLIGATIONS* (1979).

104. *Id.* at 80-82.

105. *Id.* at 83.

106. See LOCKE, *supra* note 102.

Locke's notion of tacit consent is analogous to an act of trusteeship based on an original contract, which is drafted by the founders/fathers of the Commonwealth or the Constitution. The terms of this contract are not questioned or negotiated; they are self-evident truths.<sup>107</sup>

Where and how does consent exist in these conditions? Locke believes that individuals are interested in certain "enjoyments" granted by the state. Taking the state's enjoyments implies consent, individual consent to *both* the enjoyments and their corollaries or inherent costs.<sup>108</sup> In response to this claim, Simmons argues that none of Locke's consents to enjoyments are in fact genuine consensual acts. Social obligations that derive from such enjoyments do not originate from the principle of consent. These obligations arise, if at all, from other sources like gratitude or fairness.<sup>109</sup> For example, it might be a fair-play obligation to provide one's organs unintentionally, but it would not be a consensual act, or even a tacitly consensual act.

Simmons' criticism reveals the distinction between obligation-generating acts and consensual acts. He suggests that Locke's tacit consent theory fails to give an honest account of social obligations. Moreover, it demonstrates that the paradigm of choice is essential if we are to take consent seriously enough to use it in the lexicon of social actions. Since Simmons refers to tacit consent *and* at the same time emphasizes the necessity of consent as being a "deliberate undertaking," one wonders whether consent, even tacit, can be presumed.

Consider the problem of *presuming* a deliberate, intentional undertaking. Tacit consent, as Simmons elaborates, includes intention and choice. Yet presumed consent has an element of guesswork that contradicts deliberation, choice, and intent. Presumed consent is expressed by the consenter in a special "tacit" mode, such as silence, or an absence of positive action, which has the same meaning as express consent. Both processes signify a deliberate undertaking. Simmons suggests practical conditions to be met before concluding that deliberate, tacit consent has been made.<sup>110</sup> Therefore,

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107. See SIMMONS, *supra* note 103; see also Hanna Pitkin, *Obligation and Consent I*, 59 AM. POL. SCI. REV. 990 (1965); see also Hanna Pitkin, *Obligation and Consent II*, 60 AM. POL. SCI. REV. 39 (1966).

108. See LOCKE, *supra* note 102.

109. See SIMMONS, *supra* note 103.

110. *Id.* at 80.

without these concrete conditions, presumed consent becomes consent by inference.

It may be unrealistic to posit tacit consent as deliberate intention. Can deliberate intention be presumed, in the context of health care, and more precisely, in the case of organ procurement? Put differently, in the context of organ procurement, do the social, organizational, and bureaucratic conditions allow silence to be so meaningful as to signify agreement, so we can honestly speak about presumptions of deliberate undertakings?

### *B. Presumed Consent, Dissent and Social Reality*

Misinterpreting silence as tacit consent to organ donation might be avoidable. In this scheme, opt-out procedures must fulfill their purposes for registering dissent adequately. Opting-out from requirements that appear to be non-mandatory can be harder than it should be.<sup>111</sup> One author has pointed out that opting-out from a default rule of presumed consent to organ procurement is "more illusory than real."<sup>112</sup>

It is likely that some people will not register a dissent to organ removal in a presumed consent system. People may prefer to passively obey the default rule, or people may not care about the issue. Overarchingly, most humans are disinclined towards active protest.<sup>113</sup> In a related statistic, a great number will not register

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111. According to contract law doctrine, opting-out from default rules is rarely easy. This very observation questions the so-called fundamental difference between default rules and mandatory. I draw this general argument from Eyal Zamir's discussion of hierarchy of rules, including default rules that govern contract interpretation and gap-filling. See Zamir, *supra* note 67.

112. Goodwin, *supra* note 5, at 35.

113. Admittedly, this phenomenon would occur in the same manner under an informed consent/presumed refusal scheme. This group of people, who passively comply with the default rule and have a bias toward status quo, whatever it is, is generally important to consider. However, I have reasons to think that this group might be relatively small in the case of organ procurement. Ronald Dworkin argues that people may disagree on hard issues such as euthanasia, abortion, but that most of them will agree on the fact that the issues are important and related to the sacred. Arguably, organ donation is a sacred issue. See RONALD DWORKIN, *LIFE'S DOMINION* (1993); see also M.A. Jacob, *Femme et foetus pendant la grossesse: deux patients et sujets de droit autonomes?*, 11 R.J.E.U.L 45 (1997). Facts appear to concur with Dworkin's point. In the research consulted, the majority of people either accept or refuse to donate their organs after death. In many surveys, there is no category called "indecisive" or "does not care."



dissent because they are not aware that they have to. They may also not know how to register an objection.<sup>114</sup>

In fact, silence can be interpreted as ignorance of the presumption that everyone is assumed to want to donate his or her organs after death and that opting-out is necessary.<sup>115</sup> For example, in the United States a survey conducted by Michelle Goodwin about organ transplant laws revealed that only five percent of the randomly selected respondents were aware that their state had enacted presumed consent law.<sup>116</sup> Also, in jurisdictions where a law of presumed consent has been implemented, objection to organ donation often requires relatively complex procedures. For example, a French jurisdiction requires that the refusal be formulated in front of a civil servant at a City Hall before it would be entered in the computer database.<sup>117</sup> Problems could arise for those who do not understand the jurisdiction's official languages.<sup>118</sup>

In the same manner, people who have uncertain status as residents; people with criminal records who may have reason to avoid State authorities; and people who find it intimidating to solemnize their dissent in an institutional setting would all find themselves in a compromised position. For another example, in jurisdictions where the opt-out must be expressed on a driving license or an identity card,<sup>119</sup> one wonders how an undocumented or homeless person would indicate dissent. Elsewhere, a patient's opposition to organ removal must be made in writing; this is a hurdle for less-educated and illiterate individuals.<sup>120</sup> In Brazil, millions of workers could lose their jobs for taking time off work during business hours to register on the opt-out list. People with language vulnerabilities, linguistic minorities, as deaf-world activists call them, would also face a

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114. See Robert M. Veatch & J.B. Pitt, *The Myth of Presumed Consent: Ethical Problems in New Organ Procurement Strategies*, 27:2 TRANSPLANTATION PROCEEDINGS 1888 (1995).

115. M.O.R.E. REPORT, *supra* note 42, at 22. See also James F. Childress, *Ethical Criteria for Procuring and Distributing Organs for Transplantation*, 14 J. HEALTH POL. POL'Y. & L. 87 (1989).

116. Goodwin, *supra* note 5, at n.120.

117. J.Y. Nau, *Tandis que le ministre de la santé prépare une réforme France-Transplant propose un registre national des opposants au don d'organes*, LE MONDE, June 12 1992.

118. See Bailey, *supra* note 34.

119. Such as in Brazil. *Id.* at 726 n.2.

120. Such as in Austria. See LEGISLATIVE RESPONSES, *supra* note 32.

struggle to have their choice understood.<sup>121</sup> Overall, despite the impression given by some governments that it is possible to opt-out, many citizens would not: they cannot.<sup>122</sup> Even if they choose to opt out, mechanical and organizational difficulties could prevent them from lodging their choice: computer failure, loss of hard-copy documents, and accessibility problems, to name a few.

Certainly, those who live on the margins are very likely to be left out of the opt-out system. In some of the jurisdictions where presumed consent is implemented, they actually are. In the U.S., there are concerns about the potential for an overrepresentation of poor teens of color as organ suppliers.<sup>123</sup>

Silence is the mode of expression privileged by presumed consent. But in light of these observations, it is hard to believe that silence is homogeneously meaningful of a deliberate undertaking. Many “false positives”<sup>124</sup> are likely to derive from presumed consent policy. These difficulties suggest that the quality of “consent” prone to be “presumed” fails in the practical task of matching choices for organ procurement with candidacy for organ procurement.<sup>125</sup> This is the foreseen path of presumed consent.

#### V. THE PROBLEM WITH, AND THE NEED FOR, DEFAULT RULES

Since the path to opting-out is narrow and obstructed by many factors, the default rule might gradually become *de facto* mandatory.<sup>126</sup> An uncomfortable, and challenging conclusion can be drawn with regards to default rules. The phenomenon of “voluntary” becoming “mandatory” is not unique to presumed consent. As a result, opponents of presumed consent must admit that the informed consent scheme could be subject to the same criticism. In an informed consent scheme/presumed refusal (i.e., informed consent) those who want to donate organs must also opt-out from the default rule by registering (i.e., “opting-in”) as organ donor.

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121. See Anna-Miria Muhlke, *The Right to Language and Linguistic Development: Deafness from a Human Rights Perspective*, 40 VA. J. INT'L L. 705 (2000).

122. Theodore Silver uses the expression “conscripted in disguise.” Silver, *supra* note 19, at 706.

123. Goodwin, *supra* note 5, at 28.

124. J. Michael Dennis et al., *An Evaluation of the Ethics of Presumed Consent and A Proposal Based on Required Response*, at <http://www.unos.org/Resources/bioethics.asp?index=1> (last visited Nov. 7, 2003).

125. *Id.*

126. See generally Zamir, *supra* note 67.

Nevertheless, it is submitted that a presumed consent scheme creates striking social anomalies. For example, “[s]urveys show that persons of lower education are far less likely to consent to organ donation, yet it is precisely this group of people who would run the highest risk of not knowing the proper procedures for opting-out of the system.”<sup>127</sup> It is evident that almost any default rule can disadvantage those who do not have access to the tools and mechanisms to express their opposition. It will also almost always disadvantage those whose personal choices are subject to authoritative social or religious pressures. Given this premise, it is useful to take a close look at the possible injustices to the marginal person: the homeless, the disenfranchised, the illiterate, or a dissenting member within a tight and homogeneous community (internal minority) who wants to donate organs, but does not have access to a forum to express that wish. A presumed consent default rule would work for the benefit of this person. Query those who oppose presumed consent precisely *because* its opt-out mechanism is likely not to reach all the potential dissenters who do not wish to donate their organs after death; are they not disturbed by the injustice of an informed consent system? Just as with an opt-out system, information about informed consent cannot reach all potential dissenters, and thus discriminates against marginalized people who want to donate their organs after they die.

#### *A. Listening to The Voiceless Wanting to Donate*

It appears that in the context of consent to organ donation, any default rule can cause harm to the most vulnerable members of society. Is there some kind of awkward hierarchy in this harm to those who cannot express their choices, depending on which default rule is in force?

The principle of inviolability and integrity of the body in absence of consent, well grounded in positive law,<sup>128</sup> is a possible criterion to assist us in this “assessment.” Apply positive law to the example of A and B who are, for various reasons, left out of the organ procurement information system. Whatever the State will do with their bodies after they die will not be based on their wishes, but on the default rule.

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127. Veatch, *supra* note 114, at 1890 (referring to data from D.L. Manninen & R. Evans, *Public attitudes and behavior regarding organ donation*, 253:21 JAMA 3111 (1985)). See also L. Roels et al., *A Profile of People Objecting to Organ Donation in a Country with a Presumed Consent Law: Data from The Belgian National Registry*, 29:1 TRANSPLANTATION PROC. 1473 (1997).

128. See *Reibl v. Hughes*, [1980] 2 S.C.R. 880.

The presumed consent scheme has different results for each. In the first case, A cherishes the idea of donating her organs. When she dies, the presumed consent mechanism operates, and her wishes are technically fulfilled. B, on her part, does not want to be a post-mortem organ donor. Because of presumed consent, and the impossibility for her to opt-out, her body will be salvaged after her death. From the perspective of bodily integrity, her situation can be alarming. For example, imagine that B was a homeless person. Her body was not given much attention and care (that is, no meeting of minimal needs with respect to food, warm clothing and adequate housing) by the State while it was functioning and alive. In other words, her bodily integrity, while she was alive, was repeatedly violated.<sup>129</sup> The irony would be that the State, as soon as death occurs, would suddenly have not only the interest but also the presumed authority to pay close attention to B's body (e.g. the State will perform sophisticated procedures on her body: first, to insert a catheter through her skin, to flush her abdominal cavity with preservation fluid and keep her organs chilled and viable for transplants; then to slice her body and extract the wanted organs).

Supposing an informed consent scheme (or "presumed refusal") as the default rule, another two scenarios could play out. The case of B demonstrates someone who does not want to donate, could not express it anywhere, and will, technically, have her wishes respected. As mentioned, B was voiceless during her lifetime in the State, but at least, due to the default rule, her desires are not being frustrated at the end of her life her corporeality, arguably her last and ultimate site of control, is left intact.

Now look back at A, who wanted to donate her organs. Since she could not register as an organ donor, the default rule of informed consent has unhappy consequences for her. One could argue that, at least, her dead body was 'respected' and left intact, and that the State did not dare salvage her body in the interest of others without knowing her desires. However, this argument would bring little relief to A (or to A's decedents), and does not genuinely recognize her perspective. A profoundly wanted to give her organs. The value of preservation of bodily integrity, while broadly shared in society, is not

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129. Arguably, bodily integrity must be preserved by both positive acts and the prevention of negative acts. The positive act of providing very minimal requirements to live is broadly understood to be the responsibility of the State. Therefore, its neglect is a violation of the State upon the bodily integrity of the individual who cannot, for example, get basic health care.

part of A's particular vision of the good as much as the importance of giving her organs after death is.

The above shows how awkward and arduous, or even impossible, it is to determine a hierarchy of the suffering that will be caused by creating a default rule of organ procurement. It shows how impossible is the search for a lesser violation here. The argument that informed consent preserves bodily integrity most adequately is not convincing. It is true that informed consent has been, and will remain, a safeguard against most medical abuses on the body. However, a default rule of consent to organ procurement is as imposing and exclusionary as presumed consent. One choice for all is maladjusted in an area where individual empowerment is basic. Organ procurement is a delicate area. To say the least, organ procurement default rules, as they are structured and implemented today, are problematic. Query what can be done to make default rules less harmful, or which default rule has simpler and easier opt-out arrangements.<sup>130</sup>

### *B. Does A Lesser Evil Exist?*

Is the best default rule one that fosters deliberation about the issue of consent to organ procurement? Arguably, what makes a default rule known, and easy to opt-out from, is not the rule itself, but the institutions that will apply it. It is true that opting-out processes are an institutional, organizational, and bureaucratic issue with access requirements and information requirements. But it is also a legislative policy issue. The question is thus which default rules, pertaining to organ procurement, are more likely to be inclusive, and to encourage deliberation and individual positioning on the issue.<sup>131</sup>

Contract theory suggests that legislatures should sometimes purposefully supply a default rule that contradicts what almost everyone wants, or, what the stronger or better informed party of the

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130. Other avenues were possible. One could look for the default rule that is more likely to fit with the preference of most people; this would require elaborate empirical research, whereas this paper is devoted to theoretical policy-analysis. Another possibility could have been to try and find a default rule that is more likely to change attitudes towards organ donation. This avenue involves the value-question as to what is preferable between donation versus non-donation. Responding to this inevitably excludes different and dissenting views, something that I particularly attempt to avoid in this discussion.

131. I draw my argument from contract theory on the design of default rules. Specifically, I owe the inspiration to contract theorist Christopher Riley. See Christopher A. Riley, *Designing Default Rules in Contract Law: Consent, Conventionalism and Efficiency*, 20 OXFORD J. OF LEGAL STUD. 367 (2000).

contract wants. The State's interest in doing so is the protection of the most vulnerable party to the contract. The rationale is that a default rule that disadvantages the stronger and better informed party in a contract, gives this party the impetus to avoid the application of the default rule by raising the issue and bringing it within the scope of the contractual negotiations. The purpose of this default rule is to force contractors to discuss the issue, and to force them to provide an express term of their own choice.<sup>132</sup> The stronger party thus procures the most vulnerable party the opportunity to discuss and express her interests. If the default rule were in the interest of the better-informed party, the better-informed party would not broach such opportunity. It would be up to the weaker party to be informed of the default rule mechanism and to suggest an opt-out.

The analogy with organ procurement proceeds as follows. The first premise is that the medical community is interested in increasing organ donations as demonstrated earlier. Additionally, deliberative ethics is as an adequate route to decision-making about organ donation. Therefore, the second premise is that normatively, there should be exchange of information as well as individual and collective positioning on the issue of organ procurement. This suggests that the organ procurement default rule shall purposefully contradict what the most powerful party in the context, the medical community, seeks.<sup>133</sup> For the State to provide a default rule that goes against the interest of the medical community would be not to take the shortcut of the presumed consent rule, but to implement an informed consent rule. By doing so, the State would place upon medics and organ procurement organizations and relatedly, upon itself, a strong incentive to inform citizens regarding the issue covered by the default rule, to encourage them to make a choice of their own about it, and to support them in using opt-out mechanisms if it is their desire by making these mechanisms more user-friendly and accessible. These steps might help reduce the asymmetry between

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132. *See id.* Here again, we might face the seemingly unavoidable problem of imposing one vision, in that the rule imposes on those who do not care to make positive decisions. But we can hardly force anyone to deliberate and choose. If those who do not care are forced to participate, it might just give them an incentive to say "no" to distance them from the enterprise, which does not leave them alone with their decision not to decide.

133. This claim that the medical community is the strongest party ought to be qualified. One should not forget that, aside from being powerful structurally and politically, the medical community also works in collaboration with future organ recipients, who cannot be assumed to be on the powerful side.

the medical community and the citizen about the default rule. It would also help to alleviate the systematic burdens to information systems faced particularly by the marginalized. We should remember, as was elaborated above, that marginalized individuals' active participation is not of great interest for a system operating with a presumed consent regime, since their silence serves the interest in more organs. The State knows of the interest in increasing donations, and acknowledges the importance of deliberation to avoid exclusion and coercion. Accordingly, it should recognize the privileged position held by the medical community vis-à-vis possible donors, and supply a default purposefully contrary to the interest in more organ donations.

This is not to say that an informed consent scheme is more inclusive for those on the margins than a presumed consent one. Problems of access to information distribution and opt-out mechanisms can, and do, occur under both schemes. But there is strong evidence that a commitment to deliberate and informed consent is the scheme that best protects citizens on the margins. Based on the rationale that the stronger party must be controlled, the legislature has provided a model deserving application to default consent rules. According to contract theory, the stronger party would have to disclose information and negotiate with the donor. Although not perfect, such a default rule would be the lesser of the evils.

### *C. Objections and Responses*

Several objections can be raised against the above proposal. First, the rationale that applies contract theory to default organ procurement rules might be considered excessive. In most jurisdictions, the standard of informed consent to organ procurement already applies. It derives from the well-established, almost universally employed, paradigm of informed consent to health care. However, the point of this discussion was not to find a new universal rationale for informed consent to organ procurement. Rather, the purpose is much narrower; it is limited to examining already-enacted presumed consent legislation, and to provide a perspective of critiques and opposition. It is also an attempt to reinforce the commitment to the informed consent paradigm for policy-makers tempted by theories of presumed consent.

A presumed consent scheme maintains a high imbalance between the medical community and the citizens about the issue of organ procurement. In fact, within a presumed consent scheme, we query the former's incentive in disclosing information, encouraging deliberation and improving access to opt-out mechanism. On the

other hand, in an informed consent scheme, medics and organ procurement agencies are encouraged to inform citizens about the benefits of post-mortem organ procurement and to foster discussion about the issue.

After a closer look, one might wonder whether this course of action might bring precisely just what critical approaches to deliberative ethics warn against: a reductive approach to communication as a mere attempt to convince. In this case, it could take the form of mass information campaigns, or even worse, upon misinformation through public relations forces, as opposed to the cultivation of genuine communication about the issue. Acknowledging the possibility of this risk, it is submitted that it is not accentuated in the case of organ procurement. Other cases where public or private bodies want to encourage certain behaviors on the part of citizens are much more likely to obtain this result. The transfer of information about post-mortem organ procurement, and the settings to deliberate about it, should be crafted carefully so they do not render consent a mere tool that can be shaped and orchestrated by hospitals and organ procurement organizations. Behavior should not be coerced or colonized; behavior should be the result of empowerment and emancipation.<sup>134</sup> Concretely, this might mean disclosing of the "bad news" as well as the "good news" about post-mortem organ procurement.<sup>135</sup> The body will have to be cut in order to

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134. This relates to the difference between strategic actions and communicative, emancipatory exercises, as developed by Jurgen Habermas. The difference between the latter, through which the normal process of rationalization, or change, occurs, and the former, through which abnormal processes of change occur, is that strategic actions, as opposed to communicative acts, colonize the life-world. They create distorted communication. JURGEN HABERMAS, *THE THEORY OF COMMUNICATIVE ACTION* (1987); see also WHITE, *supra* note 62; see also RASMUSSEN, *supra* note 62. This distortion occurs through

voracious, but scarcely perceived technical demands of society's sub-systems, such as the economy and the political administration. These . . . create and orchestrate a social consensus so as to enhance the technical efficiency of the system; but in so doing subtly undermine the idea that consensus consists of an unforced agreement between people.

ALAN HOW, *THE HABERMAS-GADAMER DEBATE ON THE NATURE OF THE SOCIAL: BACK TO BEDROCK* 17 (1995). This operation is done within a systematic agenda for efficiency, that is, for science's "technical" interests.

135. Margaret Verble and Judy Worth suggest a framework for decision-making in organ donation, which favors providing comprehensive information, and emphasizing the importance of disclosing the bad news about organ transplantation at the risk of



remove organs and tissues. There is a possibility that the removed organs will not be transplanted due to unforeseen medical reasons. Despite the fact that the body will be respected and the procedures pain-free, all information must be disclosed to potential suppliers in any information campaign. In addition, the quality and duration of life that can ensue from organ replacement should also not be over-idealized like it often is today.<sup>136</sup>

## VI. CONCLUSION

In *Organ Donation and the Chinese Community in Ontario*,<sup>137</sup> a medical student conducts a survey in which he finds that the issue of consent is crucial for Chinese when it comes to cadaveric organ procurement. The poll shows that if before her or his death, a Chinese person has failed to sign a mandating document, their family would be unwilling to donate their organs for transplant purposes if asked by a physician. Perhaps the most revealing results are the answers to the question, "do you agree that it is important for people to tell their families whether or not they would want their organs to be donated upon death?" A clear majority, eighty-two percent, of Chinese respondents said that yes, that it was important for them.<sup>138</sup>

On the other hand, discussions conducted with Chinese physicians revealed that "the older members of the Chinese community are frightened of Western medicine in general"<sup>139</sup> and that "the first hurdle is to tackle awareness through advertising and then to find out the barriers toward organ donation."<sup>140</sup> In order to increase awareness, the suggested recommendation was to educate by providing explanation of the procedure.<sup>141</sup> Overall, the survey indirectly but unequivocally demonstrates the inappropriateness of any attempt to infer without asking, to assume agreement, and to make presumptions of consent among Chinese patients and their families with respect to cadaveric organ procurement. The emphasis

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being "less efficient." Margaret Verble & Judy Worth, *Adequate Consent: Its Content in the Donation Discussion*, 8 J. OF TRANSPLANT COORDINATION 99 (1998).

136. See RENEE FOX AND JUDITH SWAZEY, *SPARE PARTS: ORGAN REPLACEMENT IN AMERICAN SOCIETY* (1992).

137. S. MOSTOWY, *ORGAN DONATION AND THE CHINESE COMMUNITY IN ONTARIO* (M.O.R.E. Ontario 1994).

138. *Id.*

139. *Id.* at 11.

140. *Id.*

141. *Id.* at 12.

put on awareness, advertising, public health education and family communication, indicates that questions have to be asked sensitively in appropriate and understandable language. Answers should also be received clearly. Only then can a transplant procedure be performed on the deceased's body. The Chinese community highlights the practical problems an organ procurement system would pose if the diversity of potential donors were ignored in favour of immediate, short-term benefits gained by institutionalized presumptions of consent.

In a perfectly egalitarian and homogeneous society, a genuine social contract could exist, and accordingly, all people, regardless of race, religion, language, gender, socio-economic, and resident status could know about and decide whether to stay in or withdraw from a policy of presumed consent. Otherwise, in a diverse and heterogeneous society, presumed consent can result in the non-consensual harvesting of organs. This has been demonstrated to be unacceptable. Machado stresses that by increasing the possible harvest of body parts from people who do not want to donate, "presumed consent" may become organ expropriation. Such a status would "potentially de-legitimi[ze] the whole procedure."<sup>142</sup> The default rule of non-automatic organ donation seems a better default rule, as it leaves the burden of increasing the number of organ suppliers on the medical community, the most powerful actor in the organ procurement field. Informed consent refrains from taking shortcuts that run the risk of discriminatorily disturbing cultural and religious sensitivities about bodies and death.

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142. MACHADO, *supra* note 1, at 193.

