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ETHICS AND PEDIATRIC CRITICAL CARE:
A conception of a 'thick' bioethics

Master's Thesis

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Abstract

Within this thesis, I argue for an interpretive approach to bioethics in pediatric intensive care. I begin by outlining the dominant bioethical doctrine that defines standards for ethical care in critically ill children. I critique this doctrine as legalistic and acultural. Drawing largely on the ideas of Charles Taylor, I call for a reconception of bioethics and propose an interpretive framework that is centred on culture and context. Finally, I illustrate this interpretive approach through a comparative study of two cases in pediatric intensive care: the narratives of Marc and Larry.

For the late Benjamin Freedman

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Dans cette thèse, nous débattons la question d'une approche herméneutique de la bioéthique dans les soins intensifs pédiatriques. Nous commençons par donner un aperçu de la doctrine dominante en bioéthique, doctrine qui définit les normes éthiques en rapport avec les soins prodigués aux enfants gravement malades. Nous critiquons cette doctrine comme étant formaliste et aculturelle. Faisant appel dans une large mesure aux idées de Charles Taylor, nous sommes pour une nouvelle conception de la bioéthique et proposons un modèle herméneutique centré sur la culture et le contexte. Finalement, nous illustrons cette approche herméneutique à travers une étude comparative de deux cas en soins intensifs pédiatriques: les histoires de Marc et de Larry.

Acknowledgments

Writing this thesis has been a very difficult endeavor. My sources of support and inspiration are much too numerous to list here - so I will limit my acknowledgments to a few principal persons.

This entire project was predominantly inspired by the richness of the work of Charles Taylor, whose ideas on human and moral agency have fundamentally transformed my views. I am especially grateful to him for finding the time to meet with me in person.

I was privileged to work with Dawson Schultz for several years, who generously mentored me in the ideas and practice of interpretivism.

I was particularly fortunate to have the late Benjamin Freedman as my professor for my first course in bioethics. Although his conceptual orientation differed from the direction I have taken in this thesis, Professor Freedman's influence on me was profound. His analytical depth and clarity, and his attention to the particularities of a case stimulated me conceptually, while his intensity and integrity inspired me personally. I will never forget the moment I learned about his premature death, while I was working on my first draft of this thesis. I miss you Benjy.

My debt and gratitude toward Carl Elliott, my academic supervisor, is enormous. The imaginative

richness of his work and his deep personal generosity in time and patience enriched me and sustained me. Thank you so much Carl for agreeing to work with me.

Finally, I am deeply grateful to my family and dearest friends for their love and support throughout this endeavor - thank you!

> Exclusive reliance on an acultural theory locks us into an ethnocentric prison, condemned to project our own forms onto everyone else and blissfully unaware of what we are doing.
>
> Charles Taylor (1995, p.28)

Introduction

A rising number of ethical controversies have emerged regarding the medical care of children. These have centred largely on questions about "Who should decide?" and "On what basis should decisions be made?" The care of children raises complex questions about the moral agency of 'minors' and other agents that have claimed rights, responsibilities, and duties toward their welfare.

The dominant bioethical traditions, founded largely on 'legalistic' and 'acultural' frameworks, have elaborated surrogate models for decision making that recognize the dependence of minors (as well as other 'incompetents'). This has resulted in a number of debates over the rights of surrogate decision makers, competing claims to surrogate decision making, and how surrogate decision making 'ought' to be practiced.

The central thesis of this study challenges these dominant frameworks for bioethics. I will argue that ethical care involves a practice of thick interpretation. Although my research relates primarily to children, for whom the prevailing bioethical paradigm is particularly deficient, my discussion will also relate to the broader (competent and incompetent) population.

In the first section I present two bioethical cases from a pediatric critical care setting. These involve tensions surrounding life-support decisions for two critically ill boys. Both cases present disagreements between parents and medical staff, yet the disagreements differ importantly in terms of the viewpoints held by the various moral agents.

In the second section, I outline (a) the dominant North American 'doctrine' (that is, bioethical and legal norms) that defines the ethical care of children and (b) how the prevailing bioethical frameworks would address the two cases.

In the third section, I critique the prevailing universalist (largely legalistic) bioethical models as morally thin. I introduce the notion that ethical practice is 'thickly' rooted in culture and context. Drawing largely on the works of Charles Taylor, Stuart Hampshire, and Michael Walzer, as well as relevant ethnographic works from anthrolopogy, I develop a cultural framework for morality. This argues that ethical practice is inescapably framed by the traditions of practices and webs of significances inherent in the cultural context of a presenting moral problem. I propose that the analysis of ethical dilemmas requires an interpretive (contextually thick) model of bioethical practice.

In the fourth (and final) section, I relate this cultural framework to the two cases presented earlier through a process of 'thick' description and interpretation - illustrating how an interpretive approach to bioethics can look. In turn, this interpretive study suggests that bioethical dilemmas involve a collision of moral frameworks - within the context of complex relational phenomena.

I conclude by relating my study to broader implications for bioethics practice. In particular, I discuss the implications of interpretivism for the care of incompetent patients, and the relation of an interpretive bioethics with recognized ethical principles, practices, and laws.

I

Case Presentations

Although a substantial portion of the bioethics literature is centred on theoretical discussions of ethical controversies in medicine[1], bioethics aims to enrich the moral sensitivity of medical **practice**. Medical professionals turn to bioethicists to help them examine their clinical practice and ensure good care.

The 'medical case' has emerged as a medium for bridging bioethics theory with medical practice. Real-life cases confront bioethicists with the pragmatic challenge of recommending what **should** be done.

Thus, in keeping with this pragmatic focus, I present two cases. I rely on these cases to exemplify some fundamental ethical problems surrounding the medical care of children. I will also rely on 'real' cases in order to highlight the complexity of the context within which ethical questions are framed (Davis, 1991). Later, I will propose that context has central relevance to how we determine what constitutes good care and how it ought to be pursued.

Selection of the Cases

I have chosen to present two cases for a number of reasons. On the one hand, I wanted to use more than one case in order to draw broader cross-case inferences. The use of a single case (common in the biomedical literature) may be helpful toward discussing how a particular circumstance ought to be handled, yet it limits the discussion of broader implications.

On the other hand, I wanted to resist the use of a large number of cases. This would have involved a consequent limitation in the depth to which I could analyze each case. The depth and context of cases are central to the (interpretive) conceptual arguments of this thesis - thus I will need to illustrate 'thick interpretation' through the cases presented here, in support of my interpretivist position.

In an attempt to reconcile these problems, I have settled on **two** cases. In addition to providing more than one case yet still amenable to an extensive analysis of each, the duality sets a stage for a comparison (and contrast) of phenomena. A comparative case discussion can permit some delineation of things that are particular to a unique circumstance from things that are relevant across clinical encounters.

I have selected cases from a pediatric intensive care unit (PICU) because I have a significant involvement and familiarity with this setting (which I am hoping will enrich my discussion as well as enable me to relate this study back into my practice)[2]. Within this context, I have focused on cases that involve end-of-life decisions, because this is by far the most significant type of ethical dilemma I have encountered in pediatric critical care.

This type of problem raises questions about what constitutes a worthwhile life, how the worth of a child's life should be determined, how suffering and happiness should be recognized in children with altered states of consciousness or brain injury, and who should decide what is best for a child.

In an attempt to optimize the comparative analysis of this study, I have selected two cases wherein these questions presented differently. The child's conscious function as well as the views toward life (and death) held by the parents and medical staff differ significantly in the two cases.

The cases are presented, in this section, in a (literary) form that is consistent with the dominant practice in biomedical and bioethical case presentations. This will facilitate my subsequent discussion (and critique) of prevalent practices in bioethics.

Marc's Story

Marc is a 10-year-old boy who presented to the PICU with respiratory distress. He was diagnosed with mitochondrial myopathy 5 years ago which has resulted in a progressive deterioration of his neurological status. A CT scan revealed that his brain is severely degenerated; he exhibits no voluntary function; he is stiff and frequently has episodes of motor spasms with significant grimacing. His current respiratory distress has been attributed to his respiratory muscle weakness coupled with a bacterial pneumonia. During a 7-day course of appropriate antibiotic therapy, his breathing continued to deteriorate to a point where he required a respirator in order to sustain his ventilation.

Currently, his bacterial infection has been overcome and he has now been on the respirator for 2 weeks. The PICU physicians have concluded that his pneumonia was caused by an irreversible deficiency of his respiratory function - he will never be able to breathe on his own again. His current ventilator dependence superimposed on his frequent spasms and grimacing have led the medical staff to recommend a cessation of treatment - and let Marc die. Most members of the PICU medical staff have stated that it feels inhumane to continue to subject Marc to such futile suffering.

However, his parents, who have been very devoted and involved with Marc's care, have opposed any withdrawal of therapy and want him fully treated. They have indicated that they reject that his condition is irreversible on at least 2 grounds. First, they believe that the physicians may be mistaken in the grave prognosis they have drawn for him. Second, this family is highly religious (Canadian-Italian Catholic) - the parents have stated several times that they believe in miracles, and they are waiting for a miracle.

Larry's Story

Larry is an 8 1/2-year-old boy with spina bifida and an Arnold-Chiari malformation. He was admitted to the PICU 2 months ago for treatment of respiratory failure resulting from brainstem compression (by the Arnold-Chiari malformation). He is otherwise (neurologically) fully conscious and mentally alert.

In light of a number of neurosurgical procedures that he has already undergone, physicians have judged Larry's respiratory failure as end-stage (that is, irreversible). The parents have been informed that he will permanently require mechanical ventilation.

Larry's parents have been very devoted to him throughout his life and have helped him adapt to his various disabilities. They are concerned about his current and future quality of life - continuously connected to a respirator.

They have requested that mechanical ventilation be discontinued, to allow Larry to die peacefully and avoid future suffering. Although some of the biomedical staff are ambivalent about their request, most are prepared to nevertheless respect the parents' wish. However, two PICU physicians have currently expressed strong opposition toward the withdrawal of Larry's life-support, arguing that his suffering is not excessive and that he has the capabilities of enjoying a significant portion of his life.

II

Life Support and Children: Contemporary Bioethical Doctrine

General 'Principles'

The stories of Marc and Larry raise a number of bioethical issues. A fundamental problem common to both cases involves life-support decisions for children. In particular, how should such decisions be made and by whom? The biomedical and bioethical literature provides a large corpus of recommendations toward these questions. A substantial portion of this literature reiterates a dominant position on this (supported in law and a number of professional guideline reports), while a smaller portion addresses controversies surrounding this dominant position.

I begin my discussion of the published 'doctrine' in this area, by outlining the most widely shared view (within the related literature, legislation, and jurisprudence).

The American Academy of Pediatrics (AAP) Committee on Bioethics has recently published "Guidelines on Forgoing Life-Sustaining Medical Treatment" (AAP, 1994). These highlight the prevailing bioethical views in this area.

> Most children who become ill, even those with life-threatening disorders, recover to lead satisfying lives. Nonetheless, the course of disease may at times cause health care professionals and families to consider whether continued treatment truly represents the best option. Sometimes limiting or stopping life support seems most appropriate....
>
> Generally, parents give permission for the treatment of children who cannot do so themselves. However, the American Academy of Pediatrics emphasizes that physicians and parents should give great weight to clearly expressed views of child patients regarding (life-sustaining medical treatment) LSMT, regardless of the legal particulars....
>
> Many decisions regarding life support for children call for the use of the "best interests" standard. This involves weighing the benefits and burdens of LSMT. The benefits may include prolongation of life (understanding that the continuation of biological existence without consciousness may not be a benefit); improved quality of life after the LSMT has been applied....; and increased "physical pleasure, emotional enjoyment, and intellectual satisfaction"....
>
> The burdens of LSMT may include intractable pain; irremediate disability or helplessness; emotional suffering; invasive and/or inhumane interventions designed to sustain life; or other activities that severely detract from the patient's quality of life. (The phrase 'quality of life' refers to the experience of life as viewed by the patient, ie. how the patient, not the parents or health care providers, perceives or evaluates his or her existence) (AAP, 1994, 532-533).

In the Encyclopedia of Bioethics, Loretta Kopelman outlines the prevailing norms regarding medical decisions for children,

> minors (are presumed) incompetent to consent to medical treatment.... Minors generally lack the capacity, maturity, foresight, and experience to make important choices for themselves, and cannot determine what choices promote their well-being or opportunities....
>
> parents or guardians generally have legal and moral authority to make medical decisions for minor children....
>
> Parents or guardians maintain this authority as long as they promote the well-being and opportunities of those under their care, and prevent, remove, or minimize harms to their minor children. Their authority can be contested, however.
> (Kopelman, 1995, p.358).

These statements outline the dominant legal and bioethical norms defining ethical decision making for children in North America. These are part of a larger bioethical doctrine that has established an authoritative position in defining ethical biomedical practice. Much of this doctrine is rooted in the _Report on Studies of the Ethical and Legal Problems in Medicine and Biomedical and Behavioral Research_ published by the (U.S.) President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (President's Commission, 1983). This Commission sought to address the rising number of ethical controversies emerging in health care practice and research. In particular, the Report recommends:

> _Informed consent_
>
> - The voluntary choice of a competent and informed patient should determine whether or not life-sustaining therapy will be undertaken (p.3);

- ....some constraints on patient's decisions are justified. Health care professionals or institutions may decline to provide a particular option because that choice would violate their conscience or professional judgment, though in doing so they may not abandon a patient (p.3).

Incompetent patients in general

- To protect the interests of patients who have insufficient capacity to make particular decisions and to ensure their well-being and self-determination: an appropriate surrogate, ordinarily a family member, should be named to make decisions for such patients. The decisions of surrogates should, when possible, attempt to replicate the ones that the patient would make if capable of doing so. When lack of evidence about the patient's wishes precludes this, descisions by surrogates should seek to protect the patient's best interests (p.5).

Seriously ill newborns

In nearly all cases, parents are best situated to collaborate with practitioners in making decisions about an infant's care (elaborating in a footnote: There are a number of explanations for this societal allocation of authority: respect for the family and a desire to foster the diversity which it brings; the fitness of giving the power to decide to the same people who created the child and have the duty to support and protect him; the belief that a child cannot be much harmed by parental choices which fall within the range permitted by society and a willingness to bear the risks of harm this allocation entails or a belief that in most cases "harm" would be hard for society to distill and measure anyway; or simply the conclusion that the administrative costs of giving authority to anyone but the parents outweigh the risks for children and for society unless the parents are shown to be unable to exercise their authority adequately (p.214).

Parental autonomy and countervailing considerations

Families are very important units in society... Americans have traditionally been reluctant to intrude upon the functioning of families, both because doing so would be difficult and because it would destroy some of the value of the family, which seems to need privacy and discretion to maintain its significance....

> Public policy should resist state intrusion into family decisionmaking unless serious issues are at stake and the intrusion is likely to achieve better outcomes without undue liabilities. When parental decisionmaking seems not to take account of a child's best interest, however, the stage is set for public intervention (p.215).

In summary, the President's Commission Report assigned a fundamental significance to (patient) self-determination in medical decisions. When the patient is not competent to make such decisions, then a surrogate assumes decisional authority. The surrogate is required to choose in light of the patient's known preferences - and when relevant preferences are not known, as is the case with young children, decisions are to be based on the patient's best interests. The appropriate surrogate for a child patient should usually be the parents. In exceptional circumstances, where parental decisions may imperil the child's best interests, state intervention may be warranted.

This significant recognition of individual and familial autonomy refuted regulations that aimed to 'protect' disabled infants from the withholding of life-sustaining treatments, issued by President Ronald Reagan and the United States Department of Health and Human Services. The latter were legislated in response to the case of Baby Doe.

Baby Doe

Baby Doe was born in Bloomingtom, Indiana, with Down's syndrome, a tracheoesophageal fistula, and a probable heart anomaly. The parents followed the advice of their obstetrician and chose not to allow their baby to undergo 'life-sustaining' surgery that would repair the baby's fistula, on the grounds that a child with Down's syndrome could not attain an acceptable quality of life. The infant died six days later. Legal actions were undertaken to try to override the parents' and physician's decision. The trial court ruled that the parents had the right to refuse this operation for their infant (In re Infant Doe, 1982).

Subsequently, President Reagan and the United States Department of Health and Human Services issued regulations that ordered federally-funded health care facilities to provide aggressive medical treatment to disabled infants, and established a toll-free 'hotline' where cases of nontreatment could be reported. These regulations were highly contested and invalidated in the federal courts within a few weeks (American Academy of Pediatrics v. Heckler, 1983). In turn, the United States Congress developed regulations which broadened the definition of child abuse to include "withholding of medically indicated treatment" (Dellinger & Kuszler, 1995, p.1215).

Best interests

In spite of these persistent state initiatives, the recommendations of the President's Commission 'best interests standard' prevailed as the most highly accepted norm for medical decision making in (minor) children - finding recognition in numerous court decisions.

Thus, the dominant legal and bioethical framework (in North America) for medical decisions in children requires a consideration of which option best serves the child's interests - judged in terms of what a reasonable person would choose in the patient's circumstance - with a recognition of parents as the best judges of what serves the child's best interests (except under exceptional circumstances).

The citations that opened this section (from the American Academy of Pediatrics) illustrate that the principles of 'best interests' and 'surrogate decision making' have been elaborated within the American context (within bioethics, law, and biomedicine), for the care of incompetent children.

In their highly cited work on surrogate decision making, Buchanan and Brock (1990) outline a theory of decision making for incompetents that articulates the dominant models applied to the care of children. Whereas an adult is presumed competent, and therefore qualifies for the doctrine of informed consent, the competence of children is variable, according to their age as well as their condition. In the context wherein the patient is considered incompetent, the following decisional principles should apply:

Advance directive: implementing a valid advance directive, such as a "living will" or durable power of attorney, that the individual executes while competent.

Substituted judgment: acting according to what the incompetent individual, if competent, would choose.

Best interest: acting so as to promote maximally the good (i.e., well being) of the incompetent individual (Buchanan & Brock, 1990, p.10).

More particularly relevant to children, they argue,

> In cases in which there is no valid advance directive and in which substituted judgment is inapplicable, the best interest principle ought to guide decision making for the incompetent individual. The qualifier "best,".... signals the complex and comparative nature of the judgment: Some interests.... are generally more important than others in that advancing them makes a greater contribution to the individual's good.... Thus the best interest principle instructs us to determine the net benefit for the patient of each option.... The course of action to be followed, then, is the one with the greatest net benefit to the patient .... The best interest principle is clearly patient-centered because it focuses primarily upon the current and future interests of the incompetent individual. As such it must take into account quality-of-life judgments (Buchanan & Brock, 1990, p.122-123).[3]

In general, the appropriate presumption is that the family of the incompetent individual is to be the principal decision-maker (Buchanan & Brock, 1990, p.136).

In the case of a mentally impaired (incompetent) person, Elliott and Elliott (1991) have argued that deciding in terms of prior expressed wishes or substituted judgment is fundamentally flawed. These standards fail to recognize that the previously competent person (that expressed prior wishes) is not the same person as before, when he has become permanently mentally impaired.

Therefore, imagining what it would be like to be another person is to imagine the logically impossible. In their critique of substituted judgment, the authors refer to the Saikewicz case where the court ruled (on the basis of substituted judgment) to withhold chemotherapy for the treatment of leukemia in a man with an IQ of 10 - claiming to choose what a person of high intelligence would choose in this circumstance, if he had a very low intelligence. The Elliotts conclude that the court's circuitous reasoning was actually making a best interests determination. They argue that a best interests standard is the most appropriate for an incompetent person, but highlight problems inherent in the latter, namely: assuming that it is possible to imagine what it is like to be in the patient's position, assuming that a mental impairment reduces a person's quality of life, and failing to recognize the uniqueness of a particular person's subjective experience. Finally, in the context of severe mental impairment, wherein a person may be incapable of experience and desire, Elliott and Elliott question whether such a being can have interests.

Competence

The preceeding discussion highlights that the patient's competence is a central criterion for determining when a patient is considered incapable of ensuring his/her own interests, and the application of the best interests standard is justified. A considerable area of controversy surrounding the care of children involves the determination of their competence to make medical decisions.

In an early paper on this topic, Willard Gaylin (1982) argued for a shift from an absolute to a variable concept of competence in children. Following an outline of the conditions that limit competence (that is, limits of consciousness, intelligence, rationality, knowledge and perception, experience, and age), Gaylin developed a grid for a variable determination of competence for medical decision making, on the basis of 5 (contextual) phenomena: (1) risk, (2) gain, (3) risk-gain ratio, (4) social benefits of costs, and (5) the nature of the decision.

Buchanan and Brock (1990) indicate that in most American states, the law presumes that persons below the age of 18 are not competent to make medical decisions. They argue that such laws are incongruent with empirical studies of the development of decisional capacities in children, stating that

> there seem to be no significant differences between adults and children of roughly ages fifteen (some would say fourteen) to seventeen years in the general capacities that are needed for health care treatment decision making. This suggests that the presumption of competence for health care decision making that holds for adults should be extended to minors in this age range as well (p. 243).... in the nine to fourteen age period some children will demonstrate sufficient capacities to make particular decisions to be deemed competent to make them.... the very great variability among children

> of this age in decision-making capacities, as well as the very great variability in the demands made by different decisions, justifies allowing for the possibility that the very strong presumption that nine- and ten-year-olds are incompetent to decide about treatment for themselves might on occasion be rebutted (p.244).... For children below the age of nine it is probably reasonable to maintain the practice of treating the presumption of their incompetence as unrebuttable (p.245).

It is important to note that although Buchanan and Brock call for an extension of the presumption of competence in children, they state that this is only relevant when the child wishes to decide for him/herself - the child should not be "forced, pressured, or even encouraged to decide about health care for themselves when they do not wish to do so" (p.240).

Limits to parental authority

A significant controversy exists surrounding the limits of parental authority in medical decisions for their children. The parens patriae doctrine ("the state as parent") grants the state authority to override parental decisions to counter the child's best interests. A popular application of this doctrine involves the removal of children from the custody of parents judged to be abusive or neglectful (Macklin, 1995).

Following her evaluation of the competing moral norms in the context of children (such as a child's best interests versus family autonomy and privacy), Ruth Macklin (1982) argues that the child's best interests should prevail and supercede parental decisions that seem contrary to what is best for the child. Within the medical context, significant attention regarding the relative authority of state versus parents over the care of children has emerged in relation to cases involving Jehovah's Witnesses (whose religion requires a categorical prohibition of the transfusion of blood products; Veatch, 1989) and Christian Scientists (who oppose biomedical intervention altogether; May, 1995). The prevailing outcome in such cases, involving minors, has been court rulings that mandate life-saving medical interventions.

Walter Wadlington (1994) has traced the course of medical decision conflicts between parents and state, regarding the care of children. He highlights that U.S. courts in the first half of this century were reluctant to mandate state supervention of parental decisions - respecting family autonomy. However, a shift emerged in the early 1970s, whereby U.S. courts have now tended to intervene to overrule parental decisions in cases where a child's life is in danger.

A number of writers caution against (overly common) state intervention (Capron, 1982), favoring parents as the significant decision maker for the child's care and welfare. Schoeman (1985) argues that whereas the state's relationship with a child is formal, the parent's relationship is intimate and thus warrants parental authority over children's welfare, "only those decisions which reflect gross ineptitude in moral resolution, widely interpreted, should be scrutinzed and countermanded" (p.60).

Finally, a current bioethical discourse on the significance of the family challenges the moral basis of limiting parental authority on grounds of promoting the child's best interests. This work criticizes the 'atomistic' view inherent in bioethical decision making standards (such as advance directives, substituted judgment, and best interests) that requires patients and their loving intimates to make decisions solely in terms of the patient's interests. This contests the prevailing (autonomy) framework for its conception of persons as unencumbered selves and argues for a 'familial' bioethical framework (Blustein, 1993; Hardwig, 1990; Kuczewski, 1996; Nelson & Nelson, 1994; 1995; Nelson, 1992; Nelson & Nelson, 1993).

For example, Hilde and James Lindemann Nelson - in their call for a reconception of the significance of families in medical decisions - argue for a shifting away from the dominant (individualistic) view of the family as an authoritative spokesperson for the will or interests of the patient. Rather, they argue for a familial view of ethics - wherein family interests are not subordinated (and probably not 'subordinate-able') to the interests of its individual members, and a person's moral life is understood within the enmeshed intimacies and resposibilities of family life (Nelson & Nelson, 1994; 1995; Nelson, 1992; Nelson & Nelson, 1993).

Rethinking Best Interests

The principle of best interests (rooted in other forms of legal discourse) has also been scrutinized for its appropriateness in the medical context. John Arras (1985) raises a number of objections to the best interests standard. Taken to its individualistic extreme, a best interests standard for significantly impaired infants could provide a highly compelling argument for infant euthanasia - in spite of the many legitimate moral viewpoints opposing such practices, "the best interests standard presents us with staggering problems of interpretation and application" (Arras, 1985, p.106). Arras argues that this standard confronts problems with (1) the uncertainties of the child's prognosis, (2) determining which burdens are significantly relevant, and (3) settling the viewpoint from which the burdens should be assessed - the impaired child or the normal adult.

Following the line of reasoning recommended by the President's Commission, that the burdens be weighed from the infant's own perspective, Arras worries that a child-relative best-interest standard would favor treatment in severely injured infants, given that

> the best interest standard tends to view the absence of pain as the only morally relevant consideration. No matter whether the infant is doomed to a life of very short duration, no matter that the child lacks the capacity for any distinctively human development or activity; so long as it does not experience any severe burdens, interpreted from its own point of view, the fact that the child can anticipate no distinctly human

> benefits is of no moral consequence (Arras, 1985, p.121).

This "underscores our need for a supplementary standard geared to the presence or absence of distinctly human capacities... Just as the presence of unrelievable pain can preclude the attainment of those basic goods that make life worth living, so the absence of fundamental human capacities can render a life valueless, both to its possessor and to others" (Arras, 1985, p.121-122). In the context of severely impaired infants - that have no 'distinctly human capacities' - Arras regards the application of the best interests standard as a mistake.

Arras critiques the dominant approaches as seeking to establish rules for resolving conflicts between the choices of parents and the rights of children, "motivated by an illusory quest for moral certainty in an area where such certainty simply cannot be had" (Arras, 1985, p.84). He calls for an ethic of ambiguity that recognizes the complexity of decision making for severely impaired infants, "acknowledging the pull of fundamental but contradictory moral imperatives" (Arras, 1985, p.124). In this context, Arras regards the application of the best interests standard as a "search for the secret preferences of patients lacking the capacity for self-knowledge and human relations" (Arras, 1985, p.122), a search that he characterizes as a 'misguided venture.'

In contrast, he argues for "a social, intersubjective inquiry into the conditions of a valuable human life" (Arras, 1985, p.122), which he refers to as a 'relational potential standard.' Ethical care of impaired infants requires a definition of the parameters of a 'meaningful human life.' However, Arras provides very little explication of how such an endeavor should be pursued, and concedes that this process would be difficult and subject to potential abuses.

The Canadian and Quebec Contexts

Having described the dominant (American) doctrine pertaining to life support decisions in children (and the 'evolution' of these ideas), I will now move to outline the prevailing views expressed within the Canadian context. Canadian and Quebec law provides a substantial body of legislation and relevant jurisprudence that relate to the cases of Larry and Marc. These cases raise questions about the relative authority of (a) 'the sanctity of life' (that life is inherently valuable and therefore worthy of support regardless of the circumstances) and (b) 'respect for autonomous (parental) choice' (that parents ought to be free to judge what is best for a child). Therefore, I have organized my synthesis of relevant Canadian and Quebec law in relation to these fundamental principles.[4]

Given that the cases under discussion fall within the jurisdiction of Quebec, medical care is required to conform with the Quebec Civil Code (1994). In an attempt to outline the (local) legal doctrine pertinent to this discussion, I will present selected sections of the Code:

> Article 11. No person may be made to undergo care of any nature, whether for examination, specimen taking, removal of tissue, treatment or any other act, except with his consent.
>
> If the person concerned is incapable of giving or refusing his consent to care, a person authorized by law or by mandate given in anticipation of his incapacity may do so in his place.
>
> Section 14.
> Consent to care required by the state of a minor is given by the person having parental authority or by his tutor.
>
> A minor fourteen years of age or over, however, may give his consent alone to such care. If his state requires that he remain in a health or social services establishment for over twelve hours, the person having parental authority or tutor shall be informed of that fact.
>
> Section 12.
> A person who gives his consent to or refuses care for another person is bound to act in the sole interest of that person, taking into account, as far as possible, any wishes the latter may have expressed.
>
> If he gives his consent, he shall ensure that the care is beneficial notwithstanding the gravity and permanence of certain of its effects, that it is advisable in the circumstances and that the risks are not disproportionate to the anticipated benefit.

The sanctity of life

Various sources of (Canadian and Quebec) law declare the fundamental importance of the preservation of human life and have enacted laws that recognize a right to life. Section 7 of the Canadian Charter of Rights and Freedoms (1982) declares that everyone has "the right to life, liberty and security of the person." Several provinces have enacted "good samaritan" laws that "protect health care professionals and lay people from legal liability when they provide volunteer, emergency medical assistance" (Gilmour & Rosenberg, 1989, p.280).

The Criminal Code (1985), article 215, indicates that all persons are legally required to furnish what is necessary for the survival of a person under their responsibility. The Law Reform Commission of Canada states a support for the sanctity and preservation of life (Keyserlingk, 1979).

Quebec law provides additional support for the right to life. The Quebec Charter of Rights and Freedoms of the Person indicates that every human being has a right to life (article 1). The Civil Code of Quebec (1994) declares that "Every person is the holder of personality rights, such as the right to life..." (article 3). Article 13 permits medical care, without consent, in the case of an emergency when the life of a person is in danger. The Quebec Medical Code of Ethics (1981) states that the physician must practice his profession with a respect for the life, dignity, and freedom of human beings (article 2.03.01).

The sanctity of life has also been supported in the Canadian/Quebec jurisprudence. In re Dawson (Superintendent of child and family services and Dawson, 1983), the British Columbia Supreme Court rejected the decision to forgo the revision of an intra-ventricular shunt by the parents of a 7-year-old mentally retarded boy. The Court judged that the boy had a good likelihood of recovery. In re Maude Goyette (1983), the parents of a 26-month-old child with Down's Syndrome refused to consent to heart surgery. The judgment stated that the child's right to life outweighed the burdens of the surgery.

In the Procureur General du Canada v. Hopital Notre-Dame et Niemiec (1984) case, the Court authorized surgical intervention, against the will of a person awaiting deportation who swallowed a metal wire. The Court ruled that the State's interest in preserving life overrides the person's right to self-determination.

In Hopital St-Francois-D'Assise v. Lacasse et Plourde (1993), the Court authorized a blood transfusion for an infant of parents that were Jehovah's Witnesses. The parents had refused transfusions on the basis of their religious beliefs. The Court rejected the parents' wishes on the grounds that a refusal of treatment should be justified only in terms of the child's best interests.

Respect for the person's autonomous choice

Respect for the sanctity of life can conflict with a respect for a person's autonomous choice regarding his life. This respect for autonomy is grounded in the right to self-determination and the inviolability of the person. This viewpoint has evolved from the work of Immanuel Kant, who related respect for autonomy to the unconditional worth of all persons, and John Stuart Mill's argument that persons should be permitted to develop according to their personal convictions (Beauchamp & Childress, 1994, p.125).

Respect for the autonomy of persons is firmly protected in contemporary law. Section 7 of the Canadian Charter of Rights and Freedoms states that every person has a right to liberty; and this right cannot be restricted except to conform with principles of fundamental justice. The Criminal Code (article 265) regards the intervention upon a person against his will as an act of assault.

The Quebec Charter (article 1) declares that every person has a right to liberty. The Quebec Medical Code of Ethics indicates that, except in emergencies, prior to undertaking an investigation, a treatment, or research, the physician must obtain from the patient, or his surrogate, a free and enlightened authorization (article 2.03.28).

This respect for autonomy is further explicated in the Civil Code of Quebec. Article 10 states, "Every person is inviolable and is entitled to the integrity of his person. Except in cases provided for by law, no one may interfere with his person without his free and enlightened consent." As stated previously, articles 11 and 12 indicate that no person can be made to undergo care without his consent. If the person is incapable, then a person authorized by law may consent for him, acting solely in that person's interests (taking into account any wishes the latter may have expressed).

Respect for autonomy is also supported through jurisprudence. In Reibl v. Hughes (1980), the Supreme Court of Canada ruled that every competent human being has the right to decide what his body will undergo. American court rulings have respected the right for surrogate decision-makers to (freely) refuse treatment (Cruzan, 1990; Quinlan, 1976).

In Malette v. Shulman (1990) the Ontario Court of Appeal judged a physician that administered blood to a Jehovah Witness, against her will, as liable for battery.

Three prominent Quebec Court judgments ruled in favor of respect for self-determination over the sanctity of life. In Couture-Jacquet v. Montreal Children's Hospital (1986), the Court supported the mother's refusal of chemotherapy on the grounds of the mother's reasonable demonstration of the disproportionate burdens the treatments would involve for her child. In Commission de Protection des Droits de la Jeunesse v. L'Hopital pour Enfants de Montreal (1990), the Court was requested to judge on the refusal of an intraventricular shunt procedure by parents of a newborn with spina bifida and hydrocephalus. The ruling described the parents' decision as enlightened, conscientious, and responsible. Their refusal was upheld.

In Nancy B. v. L'Hotel-Dieu de Quebec (1992), the Quebec Superior Court ruled on a woman's request for cessation of life-sustaining mechanical ventilation. The judgment stated that it is not unreasonable for a physician to withdraw life-supports to let nature take its course. Such action must particularly respect the Criminal Code and Civil Code of Quebec prohibitions against interventions performed upon persons against their will. The Court authorized the cessation of treatment requested by the patient.

Limits to respect for autonomy

Although a right to autonomous choice is highly protected, this right is not absolute. The law authorizes a number of restrictions on the autonomy of persons. The Criminal Code permits the performance of blood alcohol tests (article 254), psychiatric examination, or drug detoxification against the will of persons, under certain conditions. The Civil Code of Quebec requires persons to exercise their civil rights with a respect for good faith (articles 6 & 7) and public order (articles 8 & 9). Autonomy can also be restricted in Quebec by the Loi sur la protection de la sante publique (1994). This law empowers the health minister to employ a number of mandatory public health measures, such as requiring the mandatory declaration of specific contagious diseases.

Aside from these special restrictions, the State's respect for autonomous self-determination is quasi-absolute. Indeed, common respect for the preferences of Jehovah's Witnesses illustrates the liberty that persons have to choose to forgo relatively unburdensome (medical) interventions even if it will lead to their deaths. Jurisprudence has extended this respect to mature minors, in a case involving a 15 year old Jehovah's Witness (Robb, 1994; Region 2 Hospital Corp. v. Walker, 1994).

Summary of Relevant Legal Principles

The synthesis of legal positions outlined above conveys a central importance assigned to a respect for the autonomy of the person. Most sources of law imply that the competent patient is the master of his/her destiny. A patient has a right to choose what is best for him/her. In Quebec, the Loi sur les services de sante et les services sociaux also recognizes that persons have a right to health care (Loi sur les services de sante et les services sociaux, 1994, article 5).

For the incompetent patient, the Civil Code of Quebec states that decisions about care should be made by the authorized surrogate and that such decisions be based on the patient's expressed preferences (comparable to an advance directive), the preferences the patient would have expressed as judged by a surrogate that knows his interests and values (substituted judgment), or, for a patient whose wishes are not known because he was never competent, decisions should be based on what a reasonble person would judge as in the patient's best interests (Lesage-Jarjoura, 1990, p.76; Veatch, 1989, p.112).

A highly established approach to determining what is in the patient's best interests is based on the principle of proportionality. That is, an action is in a person's best interests if the benefits are proportionately greater than the burdens (Veatch, 1989; Gilmour & Rosenberg, 1989). This principle is also supported by the Vatican in its Declaration on Euthanasia (1980). Indeed, both the Goyette and the Couture-Jacquet cases were judged on the basis of proportionality.

In summary, children of a minor age (under 14 years in Quebec) are regarded as incompetent to make medical decisions for themselves. In such cases, decision making authority is assumed by persons with parental authority (or tutorship) for the child. Decisions made for the child should select the treatment option which best serves (proportionately) the child's best interests. The practice of this decisional authority is contestable and ultimately subject to court intervention.

Critical Comments

There are a few features of these kinds of discussions that I would like to highlight. First, we can see that throughout North America, many patients and their relatives have sought legal remedies to their conflicts over medical decision making. In turn, law has taken an active interest in defining 'right action' in the context of medical decision making in general, and in life-support dilemmas in particular. This exemplifies the central role that law plays within North American culture in expressing (and enforcing) what is ethical care.

Second, given that both 'life' and 'autonomy' are highly privileged in the dominant legal and bioethical norms, this privilege would essentially silence potential moral discourse in a case where a patient (or surrogate) wanted all measures taken to sustain life - in spite of significant opposition from biomedical practitioners (as in Marc's case). Although such cases are to be judged on an individual basis in terms of the patient's best interests, when a surrogate chooses to support life, a regard for the surrogate's autonomy seems to dominate over a significant discussion of the patient's best interests. The following three cases provide exemplars of this phenomenon:

(a) in an American case, a District Court Judge ruled that a hospital had to provide life-sustaining treatment to an anencephalic infant, as requested by the parent

(McCarthy, 1993). The mother's refusal of a withholding of life-support was based on her Christian faith that all life should be protected. The judge's ruling referred to the American Constitution's protection of the free exercise of religion and parents' rights to make decisions for their minor children; (b) in a recent Canadian case, the mother of a four-month-old girl notified the popular press of a Toronto (Hospital for Sick Children) physician that intended to withdraw life-support from her daughter with a degenerative neuromuscular disorder, against the mother's wishes to continue treatment (Gazette, 1994). The physician indicated that continuing support was not in the girl's best interests and that withdrawing support was a medical decision. This case was not judged in court, although a ruling would probably have favored the mother's determination of what was best for her daughter in these circumstances. Instead, the biomedical team ceased their opposition toward the mother and provided ongoing life-support; and (c) in the case of Otto G., an adult man who suffered a cerebral vascular accident and remained in a long-term vegetative state, a family obtained a Quebec court injunction against the medical team who wanted to stop mechanical ventilation which the team felt was futile therapy. The court supported the family's wishes to preserve Otto's life, regardless of his state, which were based on their religious beliefs

(Magder & Lefebvre, 1993).

Finally, in cases involving a surrogate decision-maker (such as a parent) who disagrees with medical staff and wishes to forgo life-support, the courts will then be more likely to employ a best interests determination and give particular attention to the circumstances of the individual patient. In related Quebec cases, the courts have sometimes overruled parental refusal of life-sustaining care (In re Maude Goyette, 1983) and sometimes supported such refusals (Couture-Jacquet v. Montreal Children's Hospital, 1986; Commission de Protection des Droits de la Jeunesse v. L'Hopital pour Enfants de Montreal, 1990). These judgments invoked an examination of proportionality (Veatch, 1989): judging if the likely benefits of treatment were proportionately greater than the consequences.

A Bioethical/Legal Commentary on the Cases of Marc and Larry

Having mapped out the viewpoints that dominate contemporary bioethical discourse relating to life-support decisions for children, I will return to the cases of Marc and Larry. If these cases were referred to me as a bioethicist, how would the dominant paradigm of the discipline guide my recommendations?

In principle, the patient ought to be permitted to choose freely to accept or refuse life-support. Both of these cases involve minors, who are consequently incompetent to choose medical treatments for themselves. Therefore, their parents are presumed to be their surrogate decision makers. The parents have a right and obligation to choose whether life-support should be maintained for their children. They should make their decision in terms of what is in their child's best interests. If the clinical staff questions the parents' consideration of the child's interests, then the former could request 'state intervention' from the courts.

A fundamental problem that underlies such cases is the determination of the best interests of a significantly disabled child. How much of which benefits matter and how much of which burdens matter?

Marc's case involves a clear disagreement between the parents and the clinical staff regarding what is best for the boy. Given that the parents regard Marc's life as worthwhile, in spite of its burdens, the clinical staff can express their views (to the parents) that his suffering is disproportionately burdensome - that they should not be expected to administer interventions that they view as contrary to their patient's interests. But, if the disagreement persists and the staff still feels categorically opposed to continuing life-support, they can seek to transfer Marc to another setting that is agreeable to providing the care required by the family. Given that the setting of the conflict is in a regional tertiary care centre, such an option is unlikely. Finally, if no other setting is available, the clinical staff can request a court judgment to overrule the parents' decision - which I suspect would probably favor the parents' decision to support Marc's life.

In Larry's case, if the involved clinical staff disagree with the parents' wishes to discontinue life-support, they cannot unilaterally provide care against the parents' wishes. The staff can clearly express their disgreement with the parents. But, if the disgreement persists, they should not be obligated to withdraw care they view as essential to their patient's interests. It could be argued that they could transfer Larry's care to another setting that would be agreeable to withdrawal of life-support - although I suspect that their consciences would likely impede such a course. Finally, the staff could request the court to overrule the parents' decision and mandate the provision of life-support.

In each of these scenarios, the parents could also seek transfer to another setting or request court intervention to implement their views of what is best for their child.

In spite of all of these potential courses of action, the underlying ethical dilemmas persist. Transferring care to another setting, or obtaining a court ruling does not resolve the initial problem - disagreement on what is the right thing to do for these critically ill children.

Pervasive in the dominant bioethical framework is a paradigm of legalism: the notion that irreconcilable disagreements should ultimately be addressed in the courts. In light of the active pursuit of court action sought by patients and their families as well as the active involvement that legislators have taken in this area, a bioethicist cannot disregard the role (and rule) of law.

However, while attention to the law can serve to uphold the rights of the parties involved, the adversarial nature of court intervention will likely not resolve (and possibly exacerbate) some of the fundamental ethical tensions of these cases. Given that a court ruling would judge one party as right (and the other as wrong), some significant moral malaise would likely persist. For example, it is foreseeable that the 'losing' party would have significant difficulty living with the enactment of a practice they viewed as wrong, and the 'opposing' parties would not be able to work together to care for the particular child, among other potential problems.

Although the various (legal and bioethical) norms that outline how ethical care ought to be administered have fostered some important advances in the moral sensitivity of modern medical care (such as the countering of paternalism, gross injustices, excessively burdensome intervention, to name a few), the dominant bioethical paradigm is significantly deficient in addressing ethical problems of a particular case. Ethical dilemmas within a clinical context involve moral tensions that persist in spite of 'conventional' bioethical intervention.

In light of these problems, I will now critique the dominant bioethical paradigm, and outline its significant limitations in adequately addressing particular clinical cases.

III

A Critique of 'Mainstream' Bioethics

In this section, I present a critique of the dominant framework employed to address ethical problems in contemporary biomedicine. Specifically, I criticize bioethics as legalistic, overly reliant on a 'respect for autonomy,' and socially inattentive.[5] This critique leads me into a discussion of the philosophical foundations of moral discourse.

Legalism

> Scarcely any political question arises in the United States that is not resolved, sooner or later, into a judicial question. Hence all parties are obliged to borrow, in their daily controversies, the ideas, and even the language, peculiar to judicial proceedings.... The language of the law thus becomes, in some measure, a vulgar tongue; the spirit of the law, which is produced in the schools and courts of justice, gradually penetrates beyond their walls into the bosom of society, where it descends to the lowest classes, so that at last the whole people contract the habits and the tastes of the judicial magistrate (de Tocqueville, 1835/1945, p.280).

The preceeding section highlighted the prominent role law has served in the emergence of bioethics. I illustrated how the cases of Marc and Larry, within contemporary bioethics, would be interpreted largely in terms of related laws and jurisprudence.

Although this reliance on law (which I shall refer to as legalism) offers some useful resources to bioethics, it also gives rise to substantial problems. Carl Schneider (1994; 1996) has articulated a critical study of the relation of law to bioethics. Whereas bioethics can rely on law for its rich language and concepts, as well as its tools for action, Schneider argues that (1) the language of law is inapt for addressing bioethical problems, and (2) that it often fails to achieve its intended effect.

Schneider traces the problems with law in bioethics to the former's role as a device for social regulation. Law aims to set minimum standards for human behavior. Through the course of its experience in social regulation, law has elaborated a language (of social regulation) that expresses its central idioms. Schneider discusses three ideas in law that have emerged as particularly influential to bioethics: (1) law's dispute-resolution function, (2) its facilitative function, and (3) its rights discourse.

Dispute-resolution in law is pursued largely through tort law, which aims to remedy a dispute between parties wherein one party was injured, as well as establish standards for social behavior. The principle of informed consent, fashioned on tort law, aims to define a standard of physician conduct, and prevent disputes over wrongful injuries.

The facilitative function of law aims to help people organize their relations. In law, this is promoted largely through contract law. Relevant examples for bioethics include living wills and durable power of attorney.

Finally, law assigns rights to persons that aim to ensure individual freedom, self-determination, and protection from mistreatment. In bioethics, this involves a recognition that persons are entitled to freely choose and refuse medical treatments.

These 'legal idioms' aim to (1) protect (vulnerable) patients from involuntary intervention, (2) provide patients with contractual options through which they can express their relevant preferences, and (3) offer patients a course of action that they can pursue if they feel they have been wrongfully injured. While these idioms define some minimal standards for medical conduct, Schneider cautions that they are also significantly problematic.

Schneider argues that the language of law is inapt. "The language of the law must give up something - and sometimes a great deal - in precision and sensitivity because of the contexts in which law is actually applied" (Schneider, 1994, p.20). Consequently, the law is vague in explicating what one is supposed to do in a specific situation. For example, the doctrine of informed consent cannot specify precisely what a physician is required to tell a patient because this will vary across contexts. The same problem arises in relation to the best interests standard. Best interests cannot be defined precisely and also be applicable across a wide diversity of contexts.

Schneider asserts that law often fails to achieve its desired effect because it is only partly relevant to the complex lives of persons. He interprets the low usage of advance directives as an example of the incongruence of the priorities of law with the everyday preoccupations of persons - where the language of law competes with the languages of religion, morality, love, friendship, pragmatism, social accommodation, custom, and compromise (Schneider, 1994, p.21).

Schneider also argues that legal discourse directly conflicts with moral discourse because law aims to arrive at an authoritative conclusion. This preempts moral discourse that should aim to debate the problem, seek mutual understanding, and work toward agreement (Schneider, 1996).

Finally, Schneider raises a particular warning concerning law's language of rights.

> Thinking in terms of rights encourages us to ask what we may do to free ourselves, not to bind ourselves. It encourages us to think about what constrains us from doing what we want, not what obligates us to do what we ought. Legal rights are tellingly different from moral rights in this

> respect: When philosophers talk about rights, they commonly talk about a complex web of relationships and duties between individuals; when lawyers talk about rights, they commonly talk about areas of liberty to act without interference (Schneider, 1994, p.21).

Rights language construes human relations as free of binds and duties. A rights-based bioethics would fail to promote the moral obligations inherent in clinical encounters. This could justify a physician distancing from his/her (autonomous) patients and "abandoning people to their rights" (Schneider, 1994, p.21).

Warren Reich (1987) has outlined several additional problems with rights language when referring to vulnerable infants: (1) there is often uncertainty over who has the obligation to satisfy the rights of the vulnerable infant; (2) the right is often impractical because the resources are not available to satisfy every right claim; (3) rights language is too adversarial - some bills of rights are directed to parents, and place parents in the role of potential adversary of the child, undermining the natural affections of most parents and the relational embeddedness of a child's moral status within a family; and (4) rights language is excessively based on autonomy, assuming

> that the moral status of human beings should be assessed in an isolationist manner, and it places autonomy above all other morally significant values in assessing moral status (Reich, 1987, p. 283).

Autonomy

Indeed, the primacy assigned to the respect for autonomy by (legalistic) bioethics has drawn additional criticisms. Sociologist Renee Fox (1996) relates this American phenomenon to the centrality of individualism in Anglo-American analytic philosophy and the individual rights-based political ideology that has pervaded American intellectual culture. This has shaped an asocial bioethical framework that systematically disregards the sociopolitical context of ethical problems (I will elaborate Fox's criticisms later).

Willard Gaylin and Bruce Jennings (Gaylin, 1996; Gaylin & Jennings, 1996) criticize the bioethical construal of autonomy for relying on an excessive notion of self-determining freedom. They refer to psychological studies of motivation and assert that behavior is far less voluntary and autonomous than bioethical discourse would commonly indicate.

They argue that: (1) a person's behavior is highly shaped by his/her environment; (2) behavior is also significantly determined by a person's past experiences; (3) social controls (such as laws) are an essential aspect of a sustainable, liberal society; and (4) appeals to emotions are far more effective in changing behavior than logical arguments, suggesting that persons are far less rational than autonomy-boosters would like to believe.

Finally, Gaylin and Jennings assert that social order can not rely solely on the voluntary and rational will of individual persons. Rather, many social goods can only be promoted through the coercive power of the law. Later in this section, I will examine autonomy further by tracing its emergence as a moral ideal.

Social Critique of Bioethics

Renee Fox (1989; 1990; 1994; 1996) has put forth the most comprehensive and sustained sociological commentary relating to bioethics. First, she provides a sociological analysis of the emergence of bioethics as a discipline in the United States. She relates this to a complex social discourse about (a) human experimentation, (b) life, death, and personhood, and (c) economics of resource allocation. Fox goes on to critique the upper middle class composition of its membership, along with its "excessive emphasis" on rights and individualism. "In its inattention to its American-ness and its assumption that its thought and moral view are transcultural, American bioethics has been more intellectually provincial and chauvinistic than it has recognized" (Fox, 1989, p.231). She has accused bioethics (rightfully, I believe) of ethnocentrism.

Fox has examined health care cost containment and economics, highlighting corporate influences upon the shape of contemporary (American) medicine (Fox, 1989, p.263). She has also argued that bioethics tends to delimit problems as moral, without consideration of the social, cultural, and political spheres of the issue. For example,

> Bioethical attention has been riveted on the justifiability of nontreatment decisions. Relatively little attention has been paid to the fact that a disproportionately high number of extremely premature, very low birth weight infants, many with severe congenital abnormalities, cared for in NICUs are babies born to poor, disadvantaged mothers, many of whom are single nonwhite teenagers (Fox, 1989, p.231).

This suggests that bioethics may have contributed to a legitimated avoidance of deep social issues, reconstrued as ethical; devoting resources and attention to the manifestations rather than the sources of the problem.

Summary

The preceeding discussion outlines a substantive criticism of the dominant frameworks employed within bioethics. These illustrate ways in which bioethics discourse is problematically abstract and distant from the socio-historical context and particularities of specific cases. In the next portion of this section, I argue for a reconception of bioethics toward a framework that is contextually 'thick' - the central argument of this thesis. I propose an interpretive bioethics.

Rethinking bioethics

The preceding critique of bioethics (as a legalistic, decontextualized, asocial framework) calls for a reconception of bioethics. Within the growing community of 'discontents,' Barry Hoffmaster has articulated a rethinking of bioethics that is particularly responsive to the problems outlined above. He argues for a turn to ethnographic method in pursuit of a bioethics that is empirically grounded in context, local knowledge, and practices:

> Ethnographic studies can make important critical and constructive contributions to our understanding of morality. On the critical side, the results of ethnographic investigations challenge both the dogmas that pervade the received view of medical ethics and the underlying philosophical model upon which 'applied ethics' is predicated. On the constructive side, ethnographic work reveals that morality must be understood contextually, and once that broader, more realistic perspective is adopted, it provides a sobering appreciation of the prospects for moral reform (Hoffmaster, 1992, p.1425).

This 'ethnographic turn' implicitly involves a centering on culture. Hoffmaster cites the following definition of ethnography from the 1968 International Encyclopedia of Social Science:

> Definition of ethnography: The data of cultural anthropology derive ultimately from the direct observation of customary behavior in particular societies. Making, reporting, and evaluating such observations are the tasks of ethnography.... An ethnographer is an anthropologist who attempts.... to record and describe the culturally significant behaviors of a particular society. Ideally, this description.... requires a long period of intimate study and residence in a small, well defined community, knowledge of the spoken language, and the employment of a wide range of observational techniques including prolonged face-to-face contacts with members of the local group, direct participation in some of the group's activities, and a greater emphasis on intensive work with informants than on the use of documentary or survey data (Hoffmaster, 1992, p.1430-1431).

Hoffmaster's paper aims to construe bioethical inquiry as an 'anthropological' study of human practices within their sociocultural context. This involves a conceptual (and practical) shift that can significantly address the major limitations of contemporary bioethics. Anthropology can serve to enlighten bioethical discourse through the empirical study of moral lives within their sociocultural context. I will now (critically) pursue Hoffmaster's proposed rethinking of contemporary moral discourse.

A discussion of morality in terms of cultural context, or a study of the relation of bioethics with anthropology highlights a more fundamental discourse on the relation of morality and culture: Is morality shaped by culture, or does a universal human (moral) nature shape the making of cultures (moral universalism)?

Although anthropology (and ethnography) can argue for the (cultural) grounding of practices, and their moral significance - how do we then determine what is right? Indeed, the moral stance that anthropology should adopt (how and whether the discipline should judge the moral status of practices it studies) is an object of significant analysis within anthropology itself (D'Andrade, 1995; Scheper-Hughes, 1995).

A bioethical turn to ethnography may enrich our understanding of moral life, but it will also give rise to new problems over how to reconcile the divergent traditions of discourse employed by bioethics and anthropology, in order to arrive at good decisions in the medical setting. Bioethics relies largely on a method of philosophical argumentation, without (empirical) grounding in the lived experiences and social context of the populations and practices studied. On the other hand, anthropology traces the cultural context and significances of practices that can deepen our understanding of 'local' morality, yet, many anthropologists would argue that they are not mandated in turn to judge the moral acceptability of local practices (Rosaldo, 1980). I will address this problem later in this section - in my discussion of the conceptual relationship of morality and culture.

I begin this discussion by outlining the dominant viewpoints in Western moral philosophy that have shaped bioethics ideology, aiming to articulate a philosophical argument that roots morality within culture. I will then describe how moral frameworks relate to ethnographic accounting, outlining a controversy over the moral comparability of practices, across cultures.

A fundamental tension regarding the universalism and/or relativism of morality emerges, which I aim to reconcile through an adaptation of Michael Walzer's notion of 'thick and thin moral discourse.' This will (conceptually) ground my subsequent proposal for a maximalist bioethical framework - which I will refer to as a 'thick' bioethics.

Morality: Philosophical Perspectives

Bioethics has emerged, in its current Western form, out of a diversity of influences. Although sources of bioethics could be traced from the fields of law and theology, the most prevalent bioethical framework of principlism (which I describe below) is developed from ideas in modern Western moral philosophy, particularly the 'analytic' tradition. The dominant ideas within Western analytic philosophy (excluding the later work of Wittgenstein) presumes that an advancement in our understanding of fundamental human problems is best attained through rationality and explanation - through analytical argumentation.

Contemporary thinking in Western moral philosophy may cite early sources such as Plato, Aristotle, Augustine, and Aquinas, but the most deeply adopted ideas in bioethics can be traced to post-seventeenth century discussions of deontology and utilitarianism. Deontology, commonly traced to the eighteenth century work of Immanuel Kant, grounded morality in a (18th century) German Protestant ethic of duty; duty is to be performed entirely for its own sake, regardless of the consequences. Kant's formulation was developed from a central 'categorical imperative' which stated "Act only on that maxim whereby you can at the same time will that it should become a universal law" (Kant, 1785/1981, p.421).

Utilitarianism, initially articulated by Jeremy

Bentham, in seventeenth century England, but was elaborated into its more widely recognized form by John Stuart Mill (1861/1979) in the eighteenth century. This consequentialist view construes moral goodness as that act which will bring the greatest happiness (and least pain) to the greatest number of people.

These ideas set off an ongoing discourse on whether the goodness of action can be judged in terms of the duty it fulfills or the (utilitarian) consequences to which it gives rise. Regardless of how this discourse is elaborated, these views hold in common: that the good can be explicated through analytical philosophical argument, giving rise to what resembles a secular (universal) moral doctrine. Indeed, this universalist approach toward moral discourse is prevalent in contemporary scholarly work, such as John Rawls' ideal social contract theory of justice (1971).

This philosophical tradition is highly apparent in the 'principlist' framework that dominates the bioethics literature. The prevalent model of principlism in bioethics has been developed by Beauchamp and Childress (1994). This model argues that ethical issues in modern biomedicine should be resolved through a deliberation of the four principles of respect for autonomy, beneficence, nonmaleficence, and justice, and how these can be upheld in a particular case.

Although deontology and utilitarianism can be traced to a reliance on a philosophically-justified fundamental principle (that is, duty and utility, respectively), Beauchamp and Childress argue that their framework is pluralist in that they claim to draw on multiple commonly-held moral ideals. Yet, their model shares with the former a reliance on principles for content and on rational analysis for method.

The Beauchamp and Childress model has flourished within medical journals in particular. I suspect its popularity is attributable, in part, to its simplicity, providing non-philosophers with a model for moral discourse. Yet in spite of its popularity in the medical and bioethical literature, principlism has been heavily criticized within bioethics.[6]

Culture and Moral Philosophy

The universalism of the moral frameworks that I have outlined above have been critiqued within moral philosophy. These critiques argue that morality is deeply rooted in culture and context, and thus frameworks that aim to 'isolate' a central moral content are fundamentally ethnocentric and flawed.

Stuart Hampshire has argued against the 'classical moralists,' in Morality and Conflict, stating,

> (a) that there cannot be such a thing as the complete human good; nor (b) can there be a harmony among all the essential virtues in a complete life; nor (c) can we infer what is universally the best way of life from propositions about human nature (Hampshire, 1983, p.155).

Although common (sexual and reproductive) needs impose constraints on the elaboration of human life, these constraints are highly unspecific and enable a wide range of diversity across societies.

Hampshire also attacks the 'classical' endeavour to resolve moral problems within a framework of rationality. Although Hampshire recognizes a place for universal moral norms, he argues,

> This moral philosophy, defended here, asserts that there always will be, and that there always ought to be, conflicts between moral requirements arising from universal requirements of utility and justice, and moral requirements that are based on specific loyalties and on conventions and customs of love and friendship and family loyalty, historically explicable conventions (Hampshire, 1983, p.165).

A doctrine of moral harmony is flawed because conflicts **within** moral systems are inescapable.

In his argument against a universal moral framework explicated through rationality, Hampshire calls for a recognition of practices within the local system of practices, "...the custom might be one of a network of interconnected customary family relationships which could not be radically disturbed without undermining a whole valued way of life" (Hampshire, 1983, pp.167-168). Hampshire has further elaborated his project to recognize moral life within its context in his analysis of justice, in Innocence and Experience (Hampshire, 1989).

Toward a Philosophical Anthropology

In Charles Taylor's view, morality is shaped by culture; that is, within cultural frameworks of significance. In his philosophical analysis of Western modernity, Charles Taylor has put forth a sustained and penetrating argument for a cultural (versus acultural) conception of moral agency (Taylor, 1989; 1991; 1995). I will outline Taylor's central arguments in detail, because I believe he has developed a thorough analysis of the de-social-ization (that is, individualization) of Western moral discourse relevant to the critical aims of this thesis. Taylor puts forth a philosophical anthropology that grounds morality within culture.

Taylor's analysis of the modern Western self examines our understanding of Western morality. In particular, he sheds light on the notion of autonomy, which is central to the prevalent frameworks of law and bioethics. He traces contemporary regard for autonomy to a 17th century shift in conception of respect for humans. Prior to this shift, natural law was the dominant moral framework. This laid out universal moral norms that persons had to obey; persons were under law.

The socio-political philosophy of Locke and Mill articulated a move from natural law to natural rights, such as a right to life and liberty. This gave rise to a construal of moral norms as a form of social immunity and possession; someone could actually waive a right. This served to further the emerging notion of autonomy of persons fostered by Descartes and Kant through a reconception of the person as a pure rational agent.

Eighteenth-century thought textured autonomous human agency further through a shift toward inwardness, to find "the voice of nature within us." Herein lay the seed of the comtemporary authentic self, as Herder argued that every person has an original way of being human and Rousseau explained self-determining freedom, wherein every person should be free to decide that which concerns him/her.

This centering of the pursuit of individual authenticity gave rise to an inescapable (1) dissipation of a meaningful cosmic order and (2) an affirmation of the ordinary life of production and family and the avoidance of suffering. The pursuits of the self became a central aim (indeed, this is congruent with typical critical depictions of modern biomedicine, which aims to overcome the death and suffering of individual persons as an end, an ultimate good, without a framework for relating this to a broader good).

Taylor argues that the individualistic variant of authenticity of the modern West, the individualism of self-fulfillment, has narrowed and flattened morality. This has resulted from (1) a moral subjectivism, wherein moral positions are believed to be individually chosen, and (2) from the influence of social sciences which favor 'hard explanation' of human agency, and resists discussion of moral ideals. This results in a narrow and flat morality because it is disengaged from the deeper things that humans strive for. Autonomy, authenticity, or rationality have value because they appeal to some deeper values, which have remained inarticulated.

Contemporary moral philosophy has contributed to this disengagement of morality by focusing on what is right to do rather than what it is good to be. The inarticulacy of this discourse has also been attributed to pluralism, where it is argued that it is not useful to talk of moral ideals within such a diverse cultural perspective.

Taylor argues that it is mistaken to talk of human agency without consideration of a deeper moral framework. The ideal of authenticity is rooted in a deeper moral ideal of what we ought to be. A moral framework refers to an horizon of significance from which a person's life derives its identity, shape, and meaning. This refers to the constellation of valuations that form one's moral community. These valuations consist of the goods and ends of life which represent the standards by which our desires and choices are judged. Taylor refers to moral thinking as a process of qualitative discrimination, the work of arriving at a sense of what is important.

A moral framework provides the background for our moral life, for what matters. When we think about our identity or our commitments, we are thinking about where we stand within this broader horizon which is constitutive of our ideals.

Finally, Taylor roots our horizon of significance within culture. Human life takes shape and meaning from the "webs of significance" that are woven by a culture (drawing on a notion articulated by Max Weber and Clifford Geertz). Taylor conceives the self as dialogical, constituted intersubjectively through expressive exchanges with significant others. This reorients the notion of self-fulfillment. Self-fulfillment can only be realized against a background horizon of what is significant. Self-choice is only valuable if some options are more significant. However, I cannot determine what is significant, because that would render it less significant. What is significant is determined by the traditions and systems of meanings that have been shaped by my community.

The ideal of self-choice supposes that there are other issues of significance beyond self-choice. This argument counters the subjectivist depiction of the modern authentic self-determining identity. For Taylor, the ideal of authenticity requires that we discover and articulate our own identity. This process involves the **manner** and the **matter** of action. The manner of action should clearly be self-determined; what I should choose for myself is up to me. On the other hand, the matter (or the content) of my action, what counts as important, is not up to me to determine. This arises out of my culture. This re-situates the actions of persons who wish to redefine what is important, on their own. Their actions may represent free autonomous agency, but if they diverge from the dominant moral framework developed by their cultural community, their actions may not be recognized as moral.

Samuel Fleischacker (1994), in his study of morality and culture, has developed an enmeshed construal of the two. He describes cultures as 'authoritative moral traditions.' He regards tradition and authority as fundamental phenomena that shape morality and culture and engage the latter in a dialectic. "Tradition and authority are fairly clear, if not strictly empirical, marks by which to distinguish cultures and to show how and why a culture's distinctiveness can matter" (p.144). He relates tradition and authority by arguing,

> Traditions make possible institutions of authority, while authorities convey, to each new generation, the power and daily application of a tradition. We interpret the tradition to which we belong as much by accepting the authoritative word of its spokespeople as by reflecting on it ourselves. Recognition of authority lies at the heart of the trust or "faith" that I have described as our characteristic relationship to traditions (pp. 81-82).

In summary, I have outlined philosophical arguments that root morality in culture. Understanding a local culture is a necessary condition for talking about the morality of human life. I will now argue that although a 'thick' understanding of culture is a necessary condition for moral discourse, it is not sufficient. I will turn toward a discussion of cultural ethnography (centering on culture in practice), aiming to illustrate that an ethnography is premised upon an outlook that says as much about the ethnographer's moral stance as it says about 'native life.' Although ethnography aims to describe native life 'as it is,' this representation involves a process of interpretation that is inescapably shaped by the ethnographer's particular moral framework. I am claiming that a 'philosophical' commitment to a particular conception of human agency underlies an ethnographic ('empirical') study of moral life and culture (whether or not this is acknowledged by the ethnographer).

This will lead into my subsequent discussion of a cross-cultural framework where I attempt to reconcile the necessity for a local (thick) view of moral life with the view from multiple perspectives required for an analysis of disagreements resulting from divergent moral viewpoints.

Morality: Ethnographic Perspectives

Earlier in this section, I described Barry Hoffmaster's proposal for the use of ethnographic method in bioethics where he argued that bioethical inquiry should be centred on the context of moral problems. Hoffmaster defined ethnography as an approach that describes that which is culturally significant for a particular society within a particular context. He draws on an anthropological perspective which adopts culture as a central phenomenon that shapes human agency.

This foundational construal of culture is elaborated by Pierre Bourdieu (1977) through his notion of the 'habitus.' In his discussion of Bourdieu, Charles Taylor describes the habitus as,

> a system of "durable, transposable dispositions" ....; that means, dispositions to bodily comportment, say, to act or to hold oneself or to gesture in a certain way. A bodily disposition is a habitus when it encodes a certain cultural understanding. It gives expression to certain meanings that things and people have for us, and it is precisely by giving such expression that it makes these meanings exist for us (Taylor, 1993, p.58).

Building on this (foundational) view of culture, anthropologist Clifford Geertz (1973) has further characterized culture as a system of significances (which Charles Taylor draws on in his cultural notion of moral agency) - culture shapes the knowledge and practices of a particular community, and how things matter for people within that community. Geertz elaborates this conception of culture into a construal of what the aims of ethnography ought to be.[7]

> The concept of culture I espouse.... is essentially a semiotic one. Believing, with Max Weber, that man is an animal suspended in webs of significance he himself has spun, I take culture to be those webs, and the analysis of it to be therefore not an experimental science in search of law but an interpretive one in search of meaning. It is explication I am after, construing social expressions on their surface enigmatical.... What defines (ethnography) is the kind of intellectual effort it is: an elaborate venture in, to borrow a notion from Gilbert Ryle, "thick description." (Geertz, 1973, p.5-6).

Ethnography can trace the cultural systems of meanings that shape the lives of persons within a society. Ethnographic (thick) description can also identify the cultural phenomena that shape the moral status of particular views and practices. Thus, ethnography can enable a rich understanding of the local moral significance of specific practices.

However, although an ethnography aims to provide a truthful account of moral life - in the process of 'writing culture' - the ethnographer's analysis inescapably expresses her own moral outlook. That is, the moral significance attributed to the practices within an ethnography can be traced to the 'interpretive framework' employed by the ethnographer. I will attempt to illustrate this point by contrasting two prominent (anthropological) ethnographies that examine practices that an observer would almost immediately characterize as morally wrong: headhunting and female circumcision.[8]

Michelle Rosaldo (1980), in her study of headhunting among young male Ilongot natives (in the Phillipines), describes this as a practice that releases youthful energy and perptetuates authoritative relations between male youths and male elders.[9]

Although Rosaldo clearly expresses her deep discomfort with the brutality of headhunting, she invokes an interpretive method to seek to understand this practice within the local cultural horizons of significance - 'from a native's point of view.' Headhunting was morally distressing to Rosaldo, because of her cultural framework, yet the Ilongot are represented as suffering no moral tension about killing. Headhunting is construed as morally unproblematic for the Ilongot. She attributes this to the primacy of culture in shaping moral agency.[10]

For Rosaldo, the moral significance of headhunting is locally constructed by this community. Therefore, she regards the aims of ethnography as a striving to understand cultural practices through thick description of how a local (cultural) community constructs the systems of meanings, practices, and social order that determine the moral significance of a particular phenomenon (such as headhunting).

In contrast, Janice Boddy approaches her subject with an explicit political framework that she is 'bringing in from the outside,'[11] in her study of spirit possession and female circumcision within the zar cult (among Hofriyat women in northern Sudan; Boddy, 1989). She indicates early in her monograph that she "speaks largely from a feminine perspective" (p.4). Boddy is concerned with the domination of Hofriyat women within a culture that practices female circumcision. Speaking from a (feminine) political framework, Boddy interprets practices in relation to power relations and notions of domination and resistance. She puts forth a rich description of Hofriyat women as constrained and dominated, subsequently framing possession practices within a counterhegemonic discourse whereby the women strive to resist their subordination.

Boddy's account contrasts with Rosaldo's in terms of the primacy accorded to culture in shaping moral agency. Whereas Rosaldo (in her relativistic account) interprets headhunting as morally unproblematic within Ilongot culture, Boddy problematizes female circumcision as an act of domination and interprets local practices within this (universalist) moral frame.

A Cultural Framework for Moral Discourse

The universalist/relativist polemics on morality and culture that I have outlined within both philosophy and anthropology highlight a fundamental tension in moral discourse. Whereas we may recognize that morality is a highly local (relativistic) phenomenon, moral discourse often involves conflicts arising out of divergent (moral) viewpoints. This gives rise to a striving for some general (universal) notions on morality that enable a comparative examination of moral problems across contexts and viewpoints. Moral analysis and decision making require a conception of moral discourse that reconciles the tension between these (relativist versus universalist) frameworks.

In her study of moral decisions, Bette-Jane Crigger (1996) takes up this problem through an analysis of texts by James Q. Wilson, Nathan Tierney, Mark Johnson, and Leon Kass. Crigger indicates that these authors adopt (what amounts to) varying 'figure and ground' approaches wherein particular cultures develop local moral frameworks, against the background of a universal human (moral) nature. She contests their aims to articulate a moral theory that is disembodied from human experience. Crigger argues for a (less adversarial) reconciliation of the relation between the universal and the local - calling on moral theorists to come to terms with Pierre Bourdieu's notion of the habitus.

Anthropologist Richard Shweder has construed the relativist/universalist discourse as a struggle to know the world between the incomplete view of relativism and the incoherent view of universalism. Shweder 'opts' for the incomplete view, which a pluralistic anthropology can try

> to overcome by staying on the move from one cultural reality to the next. Its aim is to give what I would call the view from "manywheres," rather than the view from only here (the ethnocentric perspective), rather than the view from "nowhere in particular" (Thomas Nagel's visual metaphor for the ideal of perfect objectivity) and rather than no view at all (the view of the postmodern skeptic) (Shweder, 1996, p.4).

Stanley Tambiah (1990) (also an anthropologist), drawing on the works of Alasdair MacIntyre, Peter Winch, and Donald Davidson, has described the anthropological work of ethnography as a process of 'translation' of another people's beliefs, norms, and actions. This work "implies that there is some shared space, some shared notions of intelligibility and reasoning between the two parties;... it is not possible to approach alien concepts except in terms of the anthropologist's own criteria" (p.121). Although this suggests that the anthropologist's work is constrained by his/her own framework, Tambiah argues that the serious study of another way of life will necessarily extend the ethnographer's way of life. The process of translation between cultures requires some common measure of comparability and commensurability, but the appropriate breadth of this common measure remains a contested issue. The more an ethnographer chooses to represent a cultural account as a totality, the narrower the possibilites for comparison and commensuration will be.

Charles Taylor has argued that

> The real challenge is to see the incommensurability, to come to understand how their range of possible activities, that is, the way in which they identify and distinguish activities, differs from ours.... Really overcoming ethnocentricity is being able to understand two incommensurable classifications" (Taylor, 1982, p.99).

Tambiah (1990) describes himself as

> neither a relativist nor an anti-relativist in an absolutist or blanket sense. It is possible to take a more complex position between these extremes, and strive toward comparisons and toward general judgments wherever they are appropriate and possible, and to leave other matters in an unsettled state until better information and superior frameworks make comparative evaluations possible (Tambiah, 1990, p.129).

This discussion of translation and commensurability raises implications for moral discourse involving divergent viewpoints - calling for an analysis of the commensurablity of moral outlooks across cultural frameworks.

Thick and Thin Moral Discourse

> Minimalism, then, is quite unlike Orwell's statue, liberated from the shapeless stone. We have in fact no knowledge of the stone; we begin with the finished statue; maximalist in style, ancient, carved by many hands. And then, in moments of crisis, we hastily construct an abstract version, a stick figure, a cartoon, that only alludes to the complexity of the original. We seize upon a single aspect, relevant to our immediate (often polemical) purposes and widely recognizable. What unites us at such a time is more a sense of common enemy than the commitment to a common culture. We don't possess or admire the same statue, but we understand the abstraction. It is the product of a historical conjuncture, not of a philosophical 'in-the-beginning.' Minimalism is not foundational: it is not the case that different groups of people discover that they are all committed to the same set of ultimate values. (Walzer, 1994, p.18).

Michael Walzer (1994) has attempted to reconcile the polemics of relativism and universalism in moral discourse through a 'thick and thin' framework. Although his work focuses on moral argument within political philosophy, his ideas address my central concerns regarding the relation of morality and culture.

Walzer argues against the philosophical practice of 'isolating' a set of universal moral principles that can be related across cultures and historical periods. He strives to offer a thick description of morality - a viewpoint which he defines as "richly referential, culturally resonant, locked into a locally established symbolic system of network of meanings" (Walzer, 1994, p.xi). He supports this maximalist conception of morality through thick analyses of distributive justice and social criticism.

Distributive justice requires an understanding of the significance of goods within a society, "how such meanings are constituted and how they can be recognized" (Walzer, 1994, p.26). This analysis involves a recognition of the local differentiation and specificity of goods across a diversity of social spheres such as the market economy, political power structure, and the social status system.

> distributive justice, properly understood, is a maximalist morality. Every maximalism stands in an intimate descriptive/critical relation with its own society. For what it expresses in its idiomatic, particularist, and circumstantial style is the socially constructed idealism of **these** people. It describes the things they make and value and distribute among themselves and the personal qualities that they cultivate and mean to respect, even if they most often fail to respect them, in the course of the distributions. Minimalism, by contrast, is a simplified and singleminded morality. It works with an elementary and undifferentiated understanding of society and self, abstracted from all the actual and elaborated understandings. A minimalist view is a view from a distance or a view in a crisis, so that we can recognize injustice only in the large. We can see and condemn certain sorts of boundary crossings, gross invasions of the domestic sphere, for example, like the appearance of the secret police in the middle of the night. But we don't have much to say about the precise boundaries of the home and the family or the character of legitimate action within the kinship system (or anywhere else). Minimalism gives us no access to the range of social meanings or the specific forms of distributive complexity. We can deal justly, as agents of distribution and as critics-in-detail, only from the inside of a maximalist morality (Walzer, 1994, p.39).

For Walzer, distributive justice is relative to the social meanings that the goods being distributed hold in the lives of the people among whom these goods are distributed (Walzer, 1994, p.26). Consequently, moral discourse involves a (maximalist) understanding of how such social meanings are locally constituted and recognized among a group of people - sharing a common life - at a particular time in their history (Walzer, 1983; 1994).

Walzer relates this maximalist view of distributive justice to a discussion of "the cure of souls and the cure of bodies in the medieval and modern West" (Walzer, 1994, p.28). He traces the availability of these cures to the relative social significance of the goods they serve: eternal life versus long life, respectively.

Medieval Christians largely agreed on the reality and importance of eternal life. Thus, this society organized itself to make spiritual care universally available, through a socialized system of distribution supported with public funds and ecclesiastical laws. In contrast, the cure of bodies was regarded as less real and less important, and consequently not publicly supported.

Over time, the reality and importance of eternal life was scrutinized and supplanted by a striving for longevity (that is, long life) as a more attainable good - as advocated by Rene Descartes (1637/1960) - giving rise to a (modern) cultural pursuit of physical and mental health.

Walzer argues that this shift in the social meanings of the cure of souls and the cure of bodies resulted in a corresponding shift in their publicly funded availability.

> What is striking, however, is that no case can be made today, in the West, for the use of the state's coercive power to require religious communion or church attendance; and despite the continuing debate over health care in this country, I am inclined to say that no case can be made today for the disengagement of the state from the cure of bodies. What forms socialized care should take, exactly how egalitarian it ought to be, what scope should be allowed to the private practice of medicine, how coercive the state can be (in the case of medical testing, say, or of safety laws): all this is subject to debate, much as the extent and legitimacy of coercion in religious matters - forced attendance at church services, for example - was debated in the early modern period. But the gross structures of justice-in-cures is given in advance of these arguments. The arguments are necessarily local in character, precisely because they follow from or build upon deep cultural understandings (Walzer, 1994, p.31).

Social criticism is necessarily maximalist (or thick) (Walzer, 1987; 1994). Walzer describes particularism as the crucial human commonality. Criticism requires a dense understanding of local social systems. "Social criticism in maximalist terms can call into question, can even overturn, the moral maximum itself, by exposing its internal tensions and contradictions" (p.47). He argues that even international social critic groups, like Amnesty International, work best out of a 'local office.'

Minimalism, or thin moral argumentation, consists in the moral norms and rules that are "reiterated in different times and places" (p.17). Minimalism is always embedded in thick morality, because morality is (culturally) thick. Minimalism represents intense moral norms that are 'close to the bone.' Minimalist norms can include negative injuctions against murder, deceit, torture, oppression, and tyranny.

Walzer's framework roots moral discourse (and judgment) deeply within local culture, yet recognizes the potential for abstract spheres of convergence between cultural frameworks. Unfortunately, he does not provide much elaboration of the **process** of cross-cultural discourse. Consequently, I would like to propose a philosophical 'hybridization' by drawing on Charles Taylor's notion of a 'politics of recognition' within the multiculturalist context to fill in this void (Taylor, 1992).

Taylor relates multicultural tensions to the human need for recognition. Identity is shaped, in part, by recognition. He relates cultural calls for recognition with the comtemporary collapse of social hierarchies and the emergent notion of dignity of human beings (which calls for equal recognition for all social groups and cultures). Taylor argues against a politics of difference which aims to make judgments of equal worth across cultures. He criticizes these as an attempt to endorse, homogenize, praise the other for "being like me." This cannot be a genuine act of respect.

Instead, Taylor proposes a politics of recognition based on the premise, "All human cultures that have animated whole societies over some considerable stretch of time have something important to say to all human beings" (Taylor, 1992, p.66). A politics of recognition involves a fusion of horizons (Taylor invokes a construct developed by Gadamer, 1975). This involves a transformation of standards and developing a new vocabulary of "what constitutes worth that we couldn't possibly have had at the beginning" (p.67). In setting out to study and understand the other, I presume we share an equal worth.

> But merely on the human level, one could argue that it is reasonable to suppose that cultures that have provided the horizon of meaning for large numbers of human beings, of diverse characters and temperaments, over a long period of time--that have, in other words, articulated their sense of the good, the holy, the admirable--are almost certain to have something that deserves our admiration and respect, even if it is accompanied by much that we have to abhor and reject.... What it requires above all is an admission that we are very far away from that ultimate horizon from which the relative worth of different cultures might be evident (Taylor, 1992, p.72-73).

This formulation rejects efforts to try to come up with which culture is "right" or "most right" on a given issue. A politics of recognition sets out a work of reciprocal understanding upon which to cultivate a cross-cultural framework. This is the work that cultures and sub-cultures that are interdependent have to embark upon.

In summary, I have attempted to assemble an argument for a (maximalist) cultural construal of morality. Moral agency is culturally thick.

IV

Seeking a Thicker Bioethics

A recognition of the role of culture in morality requires a significant shift in the practice of bioethics. Decontextualized legalism and the disengaged rationality of principlism are fundamentally flawed. These universalist frameworks for ethical discourse in medicine have been contested within the philosophical and social studies literature.

On the basis of the arguments outlined in this study, I would like to propose a (maximalist) 'thick' bioethics (for a lack of a better term). Bioethical discourse will need to address ethnographic accounts of medical problems. For example, not only can bioethics no longer justify a moral analysis of euthanasia, solely through philosophical argumentation without studying what it is like to undergo or perform such a practice, but the social context within which the question is framed needs to be examined (asking: who is narrating the question, what is their circumstance, when does the question arise, whom does it affect?).

For example, Margaret Lock has conducted a (thick) comparative study of organ transplantation and brain death in Japan and North America (Lock, 1995; Lock & Honde, 1990). Whereas bioethics has construed 'transplant discourse' in terms of allocation of scarce resources and philosophical contemplation about definitions of death, Lock has examined an unarticulated social sphere of power relations that has shaped the course of transplant practice in both contexts. In particular, she traces the emergence of brain death criteria - and the implicit redefinition of death - to covert pursuits and interests within the transplantation industry, that are asserted publicly in terms of the social interests of prospective recipients and neurologically impaired donors.

Talking about what is right and wrong involves an understanding of broader traditions, their significance, and how these relate to systems of authority. Therefore bioethics will need to ground ethical analyses within the cultural frameworks described in ethnographic accounts of practices abroad and at home (examples of relevant accounts include: Anspach, 1993; Bosk, 1992; Fox & Swazey, 1992). Indeed a maximalist bioethics framework would restrain itself from entering into elaborate ethical judgments of medical practices abroad. The scope of moral agency that can legitimately be analyzed cross-culturally is significantly narrow, and inescapably expressive of the author's own maximalist morality.

In addition to drawing upon ethnographic accounts for their **content**, the practice of bioethics should seek inspiration from the **method** of ethnography. The ethnographic 'skills' of cultural translation and analysis ('fusing of horizons') should become necessary proficiencies for the practice of bioethics. Indeed, an advanced foundation in anthropology should be a necessary requirement for the preparation of maximalist bioethicists. (In turn, anthropology may be enriched by a more systematic examination of the moral dimensions of ethnography).

For example, in their study of informed consent among Native Canadians, Kaufert and O'Neil (1990) have illustrated how ethnographic methods can thicken our understanding of problems within bioethical discourse. They described how medical clinicians and Native patients conceived illness and healing in very different ways. Their relationships were characterized by significant power and control imbalances.

> For Native clients, agreements may reflect the emergence of trust relationships achieved through an extended, incremental process of exchange rather than a formal, final contract.... This relationship was strongly influenced by intermediaries;.... translators, cultural brokers and personal advocates negotiate shared meanings and influence the balance of power in cross-cultural, clinical communication.... cross-cultural consent agreements also function as integrative rituals through which participants reconcile power imbalance and negotiate clinical trust (Kaufert & O'Neil, 1990, p.60-61).

Whereas bioethical discourse has framed informed consent predominantly in terms of a (legalistic) right to self-determination, and the conditions and limits to this right, the ethnographic work of Kaufert and O'Neil has identified significant social tensions surrounding this practice. In particular, a culture-sensitive intermediary was able to relate these tensions to cultural differences and conflicts over trust and power between clinicians and patients.

Culture and Context

> Moral knowledge.... is not simply intellectual grasp of propositions; it is not even simply intellectual grasp of particular facts; it is perception. It is seeing a complex concrete reality in a highly lucid and richly responsive way; it is taking in what is there, with imagination and feeling (Nussbaum, 1990, p.152)

I have argued for a rethinking of bioethics, calling for a maximalist/cultural conception of bioethics. Also, I have discussed ways in which (anthropological) ethnography can enlighten this shift both in terms of the large corpus of cross-cultural moral knowledge that has been elaborated within the anthropology literature and in offering a methodological framework for striving toward a cultural understanding of morality.

However, although our turn to ethnography (following Hoffmaster's invitation) has served to enrich our understanding of ethics, we have entered into a 'new' style of moral discourse (albeit a culturally rich one) that has no explicated method for resolving moral conflicts. Charles Taylor has articulated a process of reciprocal 'recognition' - elaborated from Gadamer's notion of a 'fusion of (cultural) horizons' - which provides us with an abstract construal of how conflicts should be addressed. Yet, how is this practiced in concrete situations - within the clinical context in particular? This is the fundamental question I address in this final section of the thesis. I will propose and apply a 'thick' bioethics.

In order to relate my (abstract) cultural conception of morality to the (concrete) clinical setting, I will need to discuss two notions that mediate the expression of culture in an actual situation: (a) that culture can refer to a wide diversity of community affiliations, and (b) although culture has a foundational importance in shaping moral horizons, a number of contextual factors will further affect the particular moral outlook that an individual person will come to have in a specific circumstance. Here I am trying to resist an essentialization of culture whereby general inferences are drawn from a community's broad moral views. I want to ensure that the moral viewpoints of persons are not 'thinned' to a simplistic reliance on the prominant features of their cultural framework. I have argued, at length, that culture is fundamentally significant - but I also recognize that it is a complex phenomenon.

What counts as culture?

I have characterized culture as a system of significances and practices elaborated by a particular community over time. Culture emerges as an horizon against which individual experiences have particular meaning. Culture functions as a pervasive explanatory framework that shapes the way persons understand specific situations, as well as the significance of their lives in general.

In anthropological inquiry, culture is highly apparent given that these studies have typically focused on very distinctive societies. These have illustrated the fundamental significance of culture. As we turn our focus to a clinical encounter within a pluralistic Western setting, culture becomes less apparent.

In light of the conception of culture that I have outlined, various forms of community membership can 'count' as culture. Anthropology has highlighted the importance of ethnicity as a cultural phenomenon. Within a pluralistic society (such as Quebec), ethnicity is a very complex phenomenon. An individual may have immigrated from another society, or is the descendant of (first- or multi-generation) immigrants. A person's ancestry may be rooted in a common ethnicity, or a mix of foreign and local ethnicities. A person's parents may have held common or divergent religious commitments. This familial 'religious heritage' can also involve varying levels of commitment across members.

In turn, all of these phenomena interact with a continuously shifting local ethnic context that gives rise to a 'Quebec' culture - emerging within a surrounding Canadian and North American context. Thus, a person's ethnic identity can involve affiliations with a diversity of ethnic and religious communities - coming together in a very particular way in an individual person.

However, culture is not necessarily limited to ethnicity or religion. Cultural identity - as a system of significances and practices elaborated by a particular community over time - can relate to additional forms of community. For example, socioeconomic and educational factors give rise to social class communities - such as working class, middle class, upper class, welfare class, 'the homeless' - that further shape the horizons of significance of its members. For instance, membership in a particular class will affect a person's sense of acceptability toward begging or theft as a source of income.

The language(s) spoken by a person affects cultural affiliation through inclusion and exclusion in a number of social groups, and access to recreational and informational media. For example, fluency in French enables a deeper acculturation to 'Quebec culture' through employment within a francophone setting, the formation of friendships and marriages with Quebec francophones, and the use of Quebec television, radio, newspapers, magazines, and cinema.

Sexual orientation can serve as a basis for cultural identity - giving rise to 'gay culture,' 'lesbian culture,' or the dominant 'heterosexual culture.' Some forms of disabilities can give rise to cultural communities - such as a 'deaf culture,' or a 'wheelchair culture.'

For the purposes of this thesis, membership in a particular professional community can also imply a cultural affiliation. In particular, biomedical practitioners are 'initiated' into a system of knowledge and practices that shapes the way its members will interpret a clinical situation and their view of what should be done. The 'biomedical community' - holding a highly shared framework for understanding human distress and healing - has developed a tradition of bodily (and mental) intervention grounded on a moral striving to preserve the length and quality of human life. Consequently, its practitioners will view clinical situations in light of their respective professional frameworks, and infer the corresponding obligations of patients, families, and themselves. The practitioner's sense of what should be done (morally) is shaped by his/her membership in a biomedical community.

Therefore, each person involved in a clinical encounter is simultaneously affiliated with a multiplicity of (cultural) communities. These converge in a particular way in that particular person, shaping his/her particular moral outlook. Consequently, individuals within a pluralistic society can hold highly divergent moral viewpoints. Yet, these views can be traced (through thick description) to moral horizons shaped by the convergence of that person's community affiliations. In light of the complex multiplicity of sources that contribute to a person's moral outlook, understanding a person's views requires an ethnographic process of thick description.

Culture in context

As I have already discussed, a thick bioethics involves a recognition that participants enter into a clinical encounter with moral frameworks that are shaped by their respective cultural horizons. In turn, these moral frameworks undergo a particular elaboration within a specific context.

Whereas I agree with Pierre Bourdieu's (1977) notion of the habitus (that culture shapes systems of meaning, the significances of various practices, and the moral order), human experiences are contextually-specific. Within a broad cultural context, will emerge particular experiences. These experiences will vary across individuals and time. As a cultural being, I will understand a situation in terms of the system of intersubjective meanings that constitute my moral horizon - my webs of significance - yet, my own particular history, my own particular social life will further shape how I experience this encounter at this time, as the experiences of the other participants in the encounter will be particularized for them.

Thick bioethical practice

A thick bioethics that is attuned to human experience (as I have characterized it) will need to be centred on the (cultural, social, and temporal) **context** of clinical situations (Murray, 1996). A number of bioethics scholars have formulated contextualist frameworks for the practice of bioethics. These have included proponents of casuistry (Jonsen & Toulmin, 1988) and variations of interpretivism (Zaner, 1988; 1994; Leder, 1994; Carson, 1990).

Casuistry engages in a thorough contextual analysis of a particular case - relating to maxims and a relevant 'paradigm case' drawn from prior analyses. However, casuistry is self-limited as a contextualist model in that it aims to explicate notions (that is, maxims and paradigm cases) that can be applied across specific cases. Although casuistry aims to be rooted in a contextualist view of morality - a view that ought to recognize that a particular situation will present a multiplicity of 'paradigms' - Richard Zaner criticizes this framework for sliding too quickly into a search for 'universal' phenomena that can be applied across contexts (Zaner, 1993).[12]

Interpretivism

The various articulations of interpretivism described in the bioethics literature offer the most contextually-centred moral frameworks for the clinical setting. Interpretivism is premised on a conception of human agency wherein moral life is rooted in sociocultural context. An interpretive approach seeks to understand human experience through thick contextual description.

> Interpretation... is an attempt to make clear, to make sense of an object of study.... The interpretation aims to bring to light an underlying coherence or sense (Taylor, 1987, p.33).

The early relation of interpretivism to the 'human sciences' can be traced to the hermeneutical frameworks of Freidrich Schleiermacher and Wilhelm Dilthey (indeed, many current practitioners of this method continue to refer to it as hermeneutics).[13] This was subsequently elaborated by Martin Heidegger (a student of Edmund Husserl's phenomenology), followed by Hans-Georg Gadamer (a student of Heidegger).

Interpretivism is premised on the notion that understanding in human experience inescapably involves interpretation. I interpret an encounter in terms of my acquired understandings (shaped through culturally embedded prior experiences). In turn, my experience of a particular encounter will reshape my 'interpretive framework' - my system of understandings that I bring to subsequent encounters. All interpretation is necessarily particular, "We can never find a 'view from nowhere,' detached from the situatedness of human life" (Leder, 1994, p.241).

> We have to start from where we are. Where we are, however, is always some place of value, else we would never have settled there.... We do not have to discover the moral world because we have always

> lived there. We do not have to invent it because it has already been invented.... No design procedure has governed its design, and the result no doubt is disorganized and uncertain. It is also very dense: the moral world has a lived-in quality, like a home occupied by a single family over many generations, with unplanned additions here and there, and all the available space filled with memory-laden objects and artifacts. The whole thing, taken as a whole, lends itself less to abstract modeling than to thick description. Moral argument in such a setting is interpretive in character (Walzer, 1987, p.17-18, 20).

Interpretations involve qualitative distinctions of the things that have meaning for me; I continuously judge how an encounter matters to me.

> Meaning in this sense - let us call it experiential meaning - thus is for a subject, of something, in a field.... There is thus a quite legitimate notion of meaning which we use when we speak of the meaning of a situation for an agent. And that this concept has a place is integral to our ordinary consciousness and hence speech about our actions. Our actions are ordinarily characterized by the purpose sought and explained by desires, feelings, emotions. But the language by which we describe our goals, feelings, desires is also a definition of the meaning things have for us. The vocabulary defining meaning - words like "terrifying," "attractive" - is linked with that describing feeling - "fear," "desire" - and that describing goals - "safety," "possession." (Taylor, 1987, p.42).

A number of models have been proposed within bioethics that offer varying levels of congruence with the framework that I have described above (and thus I ambivalently refer to them collectively as interpretivist - realizing this grouping is contestable) - each proponent putting forth a subtly different construal. These include Richard Zaner's phenomenology (1988; 1994), Drew Leder's hermeneutics (1994), and Ronald Carson's (interpretive) discernment (1990). In spite of their distinctions, these models converge substantively. They are all premised on a detailed immersion in the clinical encounter and thick interpretation of the meanings that the encounter involves for the participants, against the background 'horizon of meanings' from which each participant has emerged.

Among the proponents of these thick contextualist models, Richard Zaner has published the most elaborated and sustained articulation. Thus, I will briefly describe his phenomenological method.

Zaner (drawing partly from the ideas of Alfred Schutz) has outlined a phenomenological framework for bioethics that is centred on the experiences of participants within the clinical encounter,

> Experience is the point of departure and return for theory: its ground and ultimate "test," what it must at once illuminate and elucidate. Experience, however, is not univocal: the patient experiences, as do all those involved in the case.... Nor is this all. Every situational participant not only experiences but interprets the encounter within his or her own biography. These encounters are also socially framed by prevailing values, written and unwritten professional codes, governmental regulations, hospital policies, unit or departmental protocols, and so on - any or all variously contributing to "what's going on" in any specific case.... To probe clinical situations phenomenologically is to work somewhat like a detective: deliberately alert to the multiple ways in which participants interrelate and variously experience and interpret one another and, within that relationship, the relationship itself.... Phenomenological method suggests that in such clinical situations, moral issues are represented for deliberation, decision, and resolution solely within the contexts of their actual occurrence (Zaner, 1994, p. 230-231).

Zaner describes phenomenological method in bioethics as a process that involves (drawing heavily from Edmund Husserl):

a) putting aside - a shifting from - all prior convictions (epoche);

b) maintaining this shifting throughout the inquiry (reduction);

c) reflective attention to the inherent intentions of particular actions (practical distantiation);

d) judging on the basis of sound (experientially relevant) evidence,

> Evidenz is strictly correlated to the modes of givenness, the ways in and by means of which the things allegedly known are encountered as 'they themselves,' as Husserl says, 'in person' (Zaner, 1994, p.232-233).

e) focusing "on the situation (people, setting, circumstances, issues) itself, for its own sake" (Zaner, 1994, p.234).

An interpretive bioethical framework is congruent with the maximalist conception of moral life that I have outlined previously. An interpretivist is centred on context and situational significances. Although interpretivism does not 'privilege' cultural webs of significance as moral horizons against which contexts should be interpreted, I hope to illustrate that the (interpretivist) notion of 'intersubjective meaning' and 'shared meanings' (Taylor, 1987) can be elaborated to enable a thick recognition of moral discourse.

Interpretivism is also "textured by a dialectical tension between the appeal to similarities (pattern recognition) and the need to be attentive and responsive to the unique features of every individual case" (Zaner, 1993, p.24). Although an interpretive approach enables rich analysis of individual cases, this should be complemented with comparative analyses that elucidate significant patterns and similarities across cases - identifying 'common' practices and meanings that the ethicist can be attuned to in subsequent cases.

Finally, whereas an ethnographer aims to articulate thick description of social life (including moral agency), an interpretive bioethicist - within the clinical setting - is required to go further. Although thick description of moral conflict is a necessary condition for maximalism, it is not sufficient - the ethicist is required/expected to enable a morally acceptable resolution of the conflict. An interpretivist enables this resolution not by serving as a moral judge or expert on what should be done (as practiced within the principlist and legalist traditions) - but by facilitating the

> complex conversational process among decision-makers, specifically by helping decision-makers think about the clinical issues in the most profoundly practical manner: that is, within their own respective moral frameworks (what is 'worthwhile'), with the aim of reaching decisions that are as consonant as possible with each participant's own respective moral framework within the given circumstances (Zaner, 1993, p.25).

This construal of bioethics is compatible with the process of cross-cultural recognition (described above) that aims to 'fuse' conflicting moral horizons. This reorients the aims of the bioethicist (away from a role of expert judge) toward that of a mediational agent (the French term for reconciliation - rapprochement - seems more fitting). Within this mediating role (aiming to bridge disparate moral views), the bioethicist also guides this process in a manner that recognizes/reconciles prevailing social and professional values (and obligations) as well as relevant laws.

Narratives of Suffering, Obligation, and Care
The Thick Lives of Marc and Larry

Having elaborated an argument for moral life as a phenomenon that is shaped by culture and particularized by context, I will now present a thick description and interpetation of the cases of Marc and Larry.[14] At the expense of causing some redundancy, I will re/present these cases within the 'new' framework I have proposed.

Marc's Narrative

Marc is a 10-year-old boy who was transferred to the PICU, from the general pediatric ward, with respiratory distress. Upon arrival, his respirations were highly labored, a blood gas analysis indicated he had significant respiratory acidosis, and his oxygenation was compromised (oxyhemoglobin saturation of 88%), in spite of receiving maximal oxygen therapy by mask (that is, 100%). It was suspected that he had a bacterial pneumonia - which is typically highly responsive to antibiotic therapy combined with appropriate supportive measures. Therefore, he underwent an endotracheal intubation, mechanical ventilation was initiated, along with a 7-day course of antibiotics. Given that he could no longer feed by mouth (because of his intubation), he received tube-feedings.

Marc is well-known to the PICU staff from an earlier encounter. When Marc was 5, he was brought by his parents to this hospital with respiratory difficulties, lethargy, and episodes of impaired motor coordination. His respirations continued to deteriorate in hospital, to a point where he was transferred to the PICU for mechanical ventilation (for 2 weeks) for the treatment of severe pneumonia. During this interval, he had a number of tonic-clonic seizures that were controlled - with some degree of difficulty - with anticonvulsant medications.

In light of the numerous neuromotor problems he exhibited, Marc underwent an extensive neurological evaluation (including a number of electroencephalograms, electromyelograms, CT scans, and a muscle biopsy). These studies were conducted over the course of several weeks - during which Marc's pneumonia was resolved, mechanical ventilation was gradually 'weaned' and withdrawn, and Marc resumed independant breathing. Preparations were being made by the PICU staff to transfer Marc to a general pediatric unit - as his condition was no longer life-threatening - when the neurology team arranged a meeting with his parents to present their diagnosis of his neuromotor problems. They told the parents that Marc had mitochondrial myopthy - a disorder that would cause 'progressive' degeneration of his neurons. The parents were told that this irreversible condition would continuously damage his brain and nerves and gradually diminish his capacities. The neurologists indicated that Marc's pneumonia was secondary to a weakening of his respiratory function. They predicted that his current limitations in breathing and eating would probably prevent him from returning home.

Marc's parents were shocked by this news - they told me (and others) that they found this unbelievable, shocking: "This can't be!" "Will Marc never be the same again?" "There must be some mistake."

Marc was transferred out of the PICU within 3 days. Subsequently, I had infrequent contact with Marc and his family. I met them briefly a couple of weeks later, where the parents told me that Marc was getting stronger and that he would be going home soon. They also mentioned that they still found the neurologists' interpretation unbelievable and that they were seeking out 'second opinions.'

At the time of Marc's (neurological) diagnosis, Marc's parents - Maria and John - had one other son, who was one year younger than Marc. Maria and John were born in Canada from parents that had immigrated from Italy. Both Maria and John spoke English with an 'Italian' accent, and made frequent reference to 'Italian ways' - they seemed very engaged (at least partly) in Italian culture (their openness in speaking of their culture with me may have been partly attributable to the fact that I am also the child of Italian immigrants and therefore shared a number of experiences and views). Maria worked (part-time) as a secretary in a medical clinic and John worked as a shipping clerk. During their encounter in the PICU, it also became apparent they were highly committed to their Catholic religious faith. They made numerous references to hoping God would save Marc, they indicated that they prayed frequently, and went to (Catholic) mass regularly.

Marc went home and neither I nor any other member of the PICU team had any further contact with Marc and his family until this current PICU admission, 5 years later. The intensivists judged that his current pneumonia was attributable to a deterioration of his neurological status.

Most of the PICU staff remarked on the striking changes that Marc had undergone over the last 5 years. Marc's physical appearance had changed remarkably. He was spastic; that is, his limbs, torso, and neck were rigidly flexed and had limited range of motion. He was unable to speak. His face was grimaced much of the time, suggesting he was frequently uncomfortable. He seemed largely unresponsive to his surroundings - he did not appear to focus his eyes, or react to the sounds of the people and things around him. He could not eat independently - he was 'spoon fed' at home. He was unable to control his excrements - this 10-year-old was completely incontinent. In the PICU, the physicians and nurses stated that they felt Marc was suffering immensely, despite the potent analgesics and sedatives he was receiving.

His parents described his status differently from the PICU staff. Maria told me that Marc was very much aware - and that staff should not dismiss that. She said that he squeezed her hand when she asked him to; that he spoke a few words and was able to tell her what he needed; that he was frequently happy at home and smiled when his siblings played with him (in addition to his 9-year-old brother, he now also had a 4-year-old sister).

Following 2 weeks of mechanical ventilation and completion of the course of antibiotic therapy, Marc's pneumonia resolved. However, the strength of his respiratory function was insufficient to permit diminution of the mechanical ventilation. The PICU physicians felt that Marc's current respiratory failure was attributable to his degenerative myopathy and was therefore end-stage; that is, irreversible. In light of this irreversibility, and the near-constant grimacing Marc exhibited, his physician and nurse met with Maria and John to (a) present their evaluation of his current condition, (b) indicate that they felt uncomfortable continuing with the invasive life-supports that "subjected Marc to severe suffering with no hope of recovery," and (c) recommend the withdrawal of life-support coupled with 'comfort' measures (the initiation of more potent sedation and analgesia, regardless of the effects this could have on his vital functions).

Maria and John immediately disagreed. They stated that Marc's life was a good one - he was loved and he gave love. They stated that they "wanted everything done." They also stated that they believed in miracles, asking the physician and nurse "don't you?" Maria and John explained, in detail, that everyone should do everything that was possible for Marc and put the rest in God's hands - that it was not up to the medical staff to interfere with God's will.

Many members of the PICU team felt that these parents were in deep denial of the facts: Marc grimaced most of the time and had pronounced tremors whenever he was handled. Not wanting to oppose the parents' wishes, the PICU team maintained the life-supports while the physicians prescribed more potent doses of sedation and analgesia (to suppress his grimacing and tremors), along with inotropic medications to support his blood-pressure (which was dropping with increases in sedation and analgesia). These increases in sedation and analgesia were questioned by the parents - they did not agree that

Marc was suffering as much as the staff said he was and they worried about him getting so much medications; they worried about the harms 'all those chemicals' could cause.

Within a couple of days, Marc became even more unstable; he developed several deep skin ulcers due to his limited mobility and diminished circulation. At this point, most members of the PICU team felt that they were torturing Marc, that maintaining invasive life-supports under these circumstances was wrong. Another meeting was held with the parents whereby Marc's physician and nurse restated that they found it wrong to continue with life-supports and told the parents that if Marc's heart was to stop, it would be futile to perform cardiopulmonary resuscitation (CPR), and therefore CPR would not be performed.

Maria and John were angered. Maria stated, "Marc is our boy, we put him on this earth, we've taken care of him every day of his life, no one knows him or loves him like we do. How dare you tell us what is best for him!" The parents left the small meeting room and stepped out of the PICU. Within two minutes Maria returned and asked to speak with me - we typically spoke once or twice daily. Maria told me that she was "fed up with everyone pushing me to kill my son. Just because he's a hard case and they don't know what else to do, they want to get rid of us. I've had it with all of you

- we're going straight to the Gazette (Montreal's leading English-language newspaper) to tell them what's going on here."

I asked Maria if she and John could meet with me privately, in my office for a few minutes (I was deeply disturbed by their interpretation of the PICU team's motives for discontinuation of life-support and the apparently irreconcilable conflicts that had erupted).

I started our meeting by telling Maria and John that I wanted to do everything I could to help them - and help them help Marc. I reminded them of the many hours I had spent with them during this PICU stay, as well as 5 years earlier - that I also cared about Marc, I cared about them - and that this conflict between them and the team could complicate Marc's getting the best possible care.

I promised them that I would try to help improve communication between them and the PICU caregivers - but in order to do so, I had to understand their point of view - which I would then try help the medical team understand. It was also my intention to try to help Maria and John understand the medical team's point of view, which I understood as a genuine concern about Marc's 'needless' suffering.

I told them that I was surprised that they felt the PICU team did not care about Marc anymore and just wanted to kill him. Maria and John explained that they 'knew' the doctors had all along been covering up the real reason for Marc's problems. Maria said she looked up (in medication reference books at the clinic she worked in) one of the anticonvulsants Marc temporarily received when he was in the PICU 5 years ago (she could no longer recall the name of the drug). She saw that it could cause brain damage, "that's Marc's problem, not mitochondrial myopathy, but - they screwed up and damaged my Marc." At this point, she and John cried and sobbed. On the basis of my familiarity with critical care and with Marc's earlier PICU course, their conclusions seemed highly implausible to me - but I sensed that they were not seeking my opinion on this.

I asked them if they had ever raised this serious concern with anyone on the medical team before. Maria indicated, "I told the neurologist when I first thought of this, a few years ago, but he just brushed it off - he even laughed at me. Then I knew he was hiding something. Then I realized that this whole thing was a big cover-up - they invented a myopathy diagnosis just to cover their asses. Well we'll see how they laugh when the truth comes out in court!" John nodded in agreement throughout Maria's comments.

They went on to explain that they completely rejected the idea that Marc's problem was degenerative. They reminded me of how they were initially told (5 years ago) that Marc would not return home - yet, he did return home and they felt he was a lot better than the doctors told them he would be. Maria said, "Marc was wronged and God will see to it that justice is served. God will make him better and show how dishonest these doctors are."

They also spoke at length about (what they referred to as) 'Italian ways' in matters of sickness. John said, "these people just don't understand our ways. When someone is sick, family has to take care of them. You have to be there all the time, and do everything - not leave them in an institution all alone. When my grandmother had a stroke and became paralyzed, my parents took her into their home and cleaned her, fed her - took total care of her. It's really tough - a lot of sacrifices - but that's life. You don't abandon family. And - you don't stop treatments and make them die. Only God decides when it's time to die."

Then, they asked me if I believed in miracles. This question made me feel uncomfortable. I was feeling encouraged by the openness of our conversation but was nervous that an affirmative response would align me with their construal of the situation (and justify waiting for a miracle) whereas a negative response might be regarded as distancing or rejecting of their interpretation of Marc's situation (which I did not want to risk).

This was not a conversation among friends (whereby I would treat personal questions as a matter of 'getting to know me'). Rather, this was a serious dialogue between parents of a critically ill child and a health professional. Therefore, I understood myself to have an obligation to draw upon prior experiences with questions like "Do you believe in miracles?" and reply in a way that would be honest yet 'therapeutic.'

I stated that, "it is hard not to believe in miracles when you see the wonders of life everywhere around us - the changing seasons, the birth of a child, the healing of a cut on a child's skin. Yet, tragedies still happen. I work in a place where I see very sad tragedies every day. I see parents everyday that are praying their child will be saved. Sometimes they are saved - sometimes they aren't. It's impossible to know what will happen." Aiming to reconcile our respective views, I mentioned that we can believe in miracles but still do everything we can to comfort suffering, "some parents pray and patiently wait for miracles, but sometimes reach a point where they feel they can't keep putting their child through the pain and suffering of waiting - that maybe their child will not be saved."

Maria and John listened quietly - they seemed attuned to these ideas. John said, "that's not different from how we feel. We're just saying that we still think there's a chance and that we should keep trying to save him." Maria nodded in agreement. Having attained a significant depth in our conversation, I raised a risky point - that I felt had immense reconciliatory value, yet had a high potential for a renewed breakdown in our dialogue. I mentioned, "isn't it possible that some of the doctors and nurses really do care about Marc and you - if you think for a moment about the soft way many of them talk to Marc, or try to touch him gently, or make the time to ask you if you have any questions and try to answer them - maybe, when some of them say they are worried about Marc's suffering, they really do care and mean well?"

Maria and John indicated that they believed many of the doctors and nurses really cared about Marc a lot - they listed about a dozen names - and said they felt bad about saying none of them cared. They said that they wished Marc could be cared for only by the people they trusted, then they would not have to spend so much energy trying to defend Marc's life. I mentioned that - with all of the many people that work in a PICU - many parents say it is hard to have trust in every person that comes along. So, sometimes the PICU team tries to organize a main doctor and nurse who will be the people in charge of the overall care for a particular child. I offered to speak to the PICU team to see if that sort of thing could be arranged for Marc. They indicated that they would very much like that and mentioned a specific doctor (Jennifer - a pseudonym) that they did trust and asked if they could work mainly with her. I ended by mentioning that the physician schedules are a complicated thing, so it would be difficult to give any guarantees (for now), but that I would meet with the PICU team to report on our discussion and help them better understand Maria and John's point of view - and try to find a better way to work together in caring for Marc. They mentioned that they felt better after this long (1 1/2 hour) conversation.

That afternoon, I met with many of the PICU physicians and nurses with the aim of giving them a synthesis of my meeting with Maria and John and fostering a renewed relationship. I briefly summarized Maria and John's views of the events leading up to Marc's current situation, and I highlighted that their distrust was a central barrier to developing effective communication and joint decision-making between the parents and the PICU team. I conveyed (and supported) the parents wish to work primarily with one physician for major planning and decision-making - and they were most comfortable with Jennifer. Jennifer agreed to serve as Marc's primary physician - although she expressed some ambivalence about being able to reconcile the current disagreements over Marc's care. She very much felt that it was not in Marc's best interests to continue with invasive life-support - that "we're actually just treating the parents."

Jennifer met with Maria and John on a daily basis to review Marc's condition and came to a tentative agreement to continue with the current life-supports as long as it would take to systematically attempt to wean Marc from mechanical ventilation so he could breath on his own and return home (for the time being, there was no explicit discussion of what should be done if his breathing would be inadequate at that point). Jennifer's necessary condition for working toward this plan was that Marc would receive as much medication as it would take to relieve his grimaces and tremors which most of the PICU staff interpreted as intense suffering. This plan unfolded with relatively few disagreements over the next two weeks - many of the PICU staff members disagreed with Jennifer's plan but were prepared to cooperate, reluctantly.

Following a total of 6 weeks of mechanical ventilation, Marc's respiratory function was mildly improved. Jennifer 'mapped out' and implemented a 3-day plan to wean him to extubation. Midway into this plan, Jennifer mentioned to the parents that they should discuss their plans for Marc, following the extubation. The physician proposed a complete neurological evaluation - including a CT scan (given that he had not had a scan for 3 years) - so they could work with a more complete understanding of Marc's current condition. Jennifer anticipated that the parents would resist this evaluation - but in fact they agreed to it if the doctor felt it would help. On the occasions that I would meet with Maria and John briefly, they told me that they appreciated Jennifer's approach. They also spoke at length about their nervousness about how Marc would do when the (endotracheal) tube was removed.

Most of Marc's neurological examination provided no new information - everything was essentially unchanged from a few months earlier. However, the CT scan was remarkable. The scan revealed a significant increase in the amount of lesions in his brain. His brain appeared largely degenerated. Many of the PICU staff (as well as myself) found the scan upsetting to look at - the brain looked mutilated.

Jennifer felt this could give the parents a less contestable view of the nature of Marc's condition - that it is degenerative, very advanced, and irreversible. The physician arranged a meeting with Maria and John where she summarized the neurological evaluation - and ended with a presentation (on an X-Ray viewing screen) of what a healthy brain looks like on a CT scan (showing an actual scan from an anonymous 'normal' child); then she showed Marc's scan from 3 years ago which had a number of small white marks (lesions) scattered throughout his brain; she ended with Marc's current scan which was mostly white - that is, degenerated. Maria and John reacted with intense crying and sobbing - saying very little, they excused themselves from the meeting.

The following day was the planned day for Marc's extubation. Maria and John told Jennifer and I that they were still very upset about the scan, saying they were 'in shock.' For the time being, they felt they could not agree to withhold a reintubation in the event that Marc's breathing would deteriorate after extubation - but said they felt torn. Maria said, "I feel so guilty thinking about these things. If he is going to die, I wish he would just die in his sleep. Then I wouldn't be responsible for letting him go."

Marc was extubated in the afternoon. His breathing was labored but he maintained a minimal level of acceptable blood gases. Through the course of the evening and night, his breathing became progressively more labored and by morning his blood gases had become significantly disordered. Jennifer told the parents that Marc was gasping for air which she felt was extremely uncomfortable for him. He could be reintubated but she really did not recommend that course because it did not offer him much of a life - or he could be given sedation that would reduce his distress. She said that this could also further weaken his breathing but indicated that if he was going to die, this would be a more humane way to die.

Maria replied, "I don't want him connected to a respirator again. Please give him what he needs to be comfortable." John nodded in agreement. A morphine infusion was started. Within a few minutes Marc exhibited markedly less grimacing and gasping. The parents called in their extended family to be with them.

Marc's respiration gradually diminished and he was declared dead two hours later.

Marc's family spent three hours with him after his death - during which he was held by his parents most of the time. As the family left the PICU, Marc's parents thanked the PICU staff for the care they gave him. A month later, I received a thank you card from them expressing their gratitude for the time I spent with them "even when they were hard on me."

Larry's Narrative

Larry is an 8 1/2-year-old boy with an Arnold-Chiari malformation that has impaired his brainstem function. Among his brainstem impairments is a diminished respiratory drive that has rendered him completely dependent on mechanical ventilation for the last 2 months. He has otherwise been fully conscious during this 2-month stay in the PICU. There is some suspicion among the neuroscience specialists that his respiratory compromise is irreversible. The parents have indicated to the PICU staff that if Larry will no longer be able to breath on his own, they would not want that kind of life for him. They would wish for life-support to be discontinued and that Larry be allowed to die peacefully.

Larry was admitted to the PICU, from a general pediatric ward, for respiratory support when his breathing became inadequate to maintain acceptable blood gases. Within a few hours he required an endotracheal intubation and mechanical ventilation which immediately improved his blood gases and has sustained him until now.

He was previously admitted to the general pediatric ward 3 months earlier for treatment of a pneumonia, which may have been precipitated by his gradual respiratory decline.

Larry is an only child of Tom and Laura. He was born in Montreal with spina bifida which caused paraplegia (that is, paralysis of his legs). When Larry was 3 years old, they moved to Alberta (to Tom's home town) where Tom had better chances of getting employment (he was a plumber but did not speak French). Laura did not seek employment so she could be home full-time with Larry, who was highly dependent.

Two years ago, they returned to Montreal for a number of reasons. First, they wanted to live close to Laura's parents - who would be able to help in caring for Larry. Both Tom and Laura said they were very devoted to Larry and to ensuring he had a good life - but this frequently made them very tired and in need of help. Second, Larry's medical condition seemed to be deteriorating - in particular, his arms were sometimes weaker and less coordinated - so they wanted to live closer to the hospital that already knew him and treated him. Finally, they were having a lot of economic difficulties 'making ends meet' with Tom's unstable income, so they chose to live with Laura's parents for a while to get their finances in better order. Two years later, they are still living with Laura's parents. Laura says she does not mind that, and in fact it has been convenient to have 'live in' babysitters. On the other hand, Tom says he feels uncomfortable living with 'the inlaws' for so long - and "can't wait" to have their own home again.

When they returned to Montreal (2 years ago), they had Larry assessed by his neurosurgeon. This revealed a significant Arnold Chiari malformation with syringomyelia that was compressing his brainstem. Consequently, Larry underwent complex neurosurgery for decompression of this malformation and insertion of a syringo-pleural shunt (which would divert fluid away from his brainstem and into his pleural space). Two weeks later he required further surgery for revision of the shunt which was not draining adequately. Then, six weeks after that, Larry underwent additional extensive neurosurgery to attempt further brainstem decompression and shunt revision because his clinical condition had not improved. No remarkable improvement resulted from this final operation. He returned home and Larry, Tom, and Laura were required to adapt to this diminished motor function. Otherwise, Larry's mental function was relatively 'normal' - except for intellectual delays that were likely attributable to the experiential limitations imposed by his motor deficits.

In light of his significant physical problems, Tom and Laura have not yet registered Larry into a school program.

Tom and Laura are both multi-generational Anglo-Canadians. In comparison with Marc's parents, Tom and Laura are much less expressive of their deeper 'world-views' (consequently, this narrative is somewhat shorter).

Tom speaks most openly of his passion for music. He plays guitar and listens to music 'all the time' - a passion which Larry has also acquired. While in the PICU, Larry spends (by far) most of his waking time listening to rock music or watching rock videos - he does not want to engage in any other types of activities such as drawing, making crafts, having stories read to him, or playing games. The PICU nurses refer to him as constantly 'plugged in' (to music).

Currently, following 2 months of mechanical ventilation in the PICU, Tom and Laura have asked Larry's neurosurgeon and the PICU physicians to evaluate his prognosis. In particular, they were concerned about his prospects for resuming independent respiration. One of the PICU physicians, George, volunteered to serve as Larry's primary physician and would try to coordinate a complex evaluation process. A thorough neurological and respiratory examination was conducted, using clinical as well as laboratory tests.

Upon completion of the various tests, George spoke with each of the involved specialists for their interpretations. There was a consensus of opinions: (1) Larry's brainstem compression had deteriorated beyond the possibility of surgical correction, (2) his respiratory failure was probably end-stage and irreversible, and (3) he will eventually develop further motor deficits as well as significant mental impairment. Although these views were shared by all of the specialists, they differed in the level of certainty and imminence they assigned to these interpretations - some predicted a certain and severe decline within a few months, whereas others predicted a probable decline in the short or long term that could range anywhere between mild and severe.

I asked George directly what he felt was Larry's prognosis and most appropriate treatment course. He replied, "I really don't know. It doesn't look good for Larry, but I'm really not sure what would be the best thing to do. I'll have to see what the parents think."

George tried to arrange a meeting between the parents and the involved specialists so that the latter could present their opinions and potential plans of care could be planned. Despite numerous attempts, George was unable to arrange a meeting time that was suitable for everyone concerned. Consequently, he scheduled meetings for the parents to meet the specialists individually -

George was present for all of these meetings.

Prior to these meetings, the parents asked George for some information on what the tests showed. George described the points of agreement and disagreement I outlined above - but emphasized that it was important to discuss these interpretations directly with the specialists - that he could not speak for them.

Tom told George, myself, as well as a number of other staff, that he did not want his boy to live on a respirator and slowly die bit by bit. If Larry had no hope of getting better, then the respirator should be stopped. Laura's view differed significantly. She agreed with Tom in not wanting Larry to suffer and live his life on a respirator. But, if there was no choice and this was all that was possible for her son - then maybe they would just have to accept that - and live with it. They spoke openly about these views - even in front of each other, where they tried to show respect for their respective views.

Whenever I discussed these views with them, they did not describe much more than what I have stated above. For example, neither made any explicit reference to a particular moral tradition or religious viewpoint that guided them in their preferences. They each referred to their extensive experience with Larry's life (with disabilities) and stated what they thought was good for Larry: for Tom, life on a respirator was not good enough for Larry; for Laura, it might be.

These were the views they held as they entered into their meetings with the various specialists - namely, a neurosurgeon, a neurologist, a pulmonologist, a home care specialist, as well as numerous ongoing meetings with George to discuss the information presented to date.

I was not present at any of the specialist meetings but followed the course of this discussion through conversations with Tom, Laura, George, the various specialists involved and from comments that the parents shared with other staff. As each specialist meeting took place - wherein the irreversibility of Larry's condition was restated - Tom's expressed wish to discontinue the respirator intensified, while Laura became progressively more silent about her views that life on a respirator might be acceptable for Larry.

When all of the specialist meetings were completed, George met with the parents to discuss what course to take for Larry. Both parents stated that they had been discussing this problem continuously and said they both wanted the respirator to be stopped, that Larry be medicated to die peacefully, so they could spare him from the discomforts of being tied to a respirator and a hospital and protect him from suffering through a slow and uncomfortable death. George told them he would discuss their wishes with the PICU team.

I was present at the PICU team meeting where

George presented the wishes of Larry's parents. Also present were 4 other PICU physicians (that is, pediatric intensivists), 2 nurses (one of whom was the principal nurse involved in Larry's care) and the social worker that had been working with Tom and Laura. George invited comments on the parents' request. Two physicians and the primary nurse stated that they respected the parents' views - that they had no doubts about the parents' intentions. They referred to the parents' extensive involvement in Larry's life, and they were confident that the parents spoke with authoritative knowledge about Larry and about life with disabilities. They had no doubts that Tom and Laura wanted what was best for Larry - that they were not simply tired of tending to his burdensome needs. The tone of the discussion was tending toward supporting the parents' request until the remaining two physicians stated that they were uncomfortable with the removal of Larry's life-support. They mentioned that if everyone else agreed with the parents, then these physicians would not obstruct such a plan but said they could definitely not enact it - "not while I'm on service; I won't be the one to do it."

This opened up a discussion wherein these physicians described some of their preoccupations. Both knew Larry well (indeed one of them was known for having become remarkably attached to Larry), and they felt that his life did not seem so bad as to warrant an ending at this time. They referred to his enjoyment of music -

that he clearly enjoyed being alive. They also questioned whether Larry's input could be sought in some way.

George mentioned that he was taken by this discussion - that it voiced a discomfort he had all along with the parents' request but found the parents would become offended if he demonstrated any resistance, or questioned them - so, not wanting to offend them, he tended to 'back down.' George concluded the meeting by stating, that as Larry's primary physician, he was questioning whether he could support Tom and Larry any further in their wishes, but would take a few days to think about it further. Two days later, this discussion reemerged at a PICU ethics education session (which was not scheduled to address this particular topic - but ended up there anyway). Following this second discussion, George concluded that he would tell Larry's parents that he and the PICU team could not comply with their request to withdraw Larry's mechanical ventilation while he was conscious and showing many signs of deriving enjoyment from his life. He told them so, the following day. Tom and Laura offered virtually no reply - other than, "well I guess there's nothing we can do." George explained, in detail, how uncomfortable he and the PICU group felt about ending Larry's life-support at this time. He also apologized for not recognizing this earlier - for having led the parents to believe that he and the PICU team may have been able to support their wishes. He explained that his own personal views only became apparent late in the course of their discussions. In spite of George's elaborate attempts to explain his viewpoint, Tom and Laura remained silent and offered no further comments at that meeting.

Larry's mechanical ventilation was maintained, Tom and Laura continued their active involvement in his care (whereby Laura spent the entire daytime with Larry, while Tom spent the evenings, after work); George continued to serve as Larry's primary physician; all of the other forms of care Larry was receiving were maintained, and Larry continued to spend most of his days enjoying his 'heavy metal' music. George, the primary nurse, the social worker, myself, as well as a number of other people made a number of overtures toward Tom and Laura to talk about their feelings toward their experience with the life-support decision. They repeatedly resisted such discussions, saying they felt bad about the way it went, that their wishes were not respected - but now there was nothing left to say. A significant silence had formed between the parents and the PICU team. Conversations were largely limited to 'small talk.'

One month following George's announcement that he would not withdraw the ventilator, he met with the parents to propose a tracheostomy for Larry. He explained that this would provide Larry with a more secure airway and would disemcumber his face - which would be more comfortable for him. Also, with a tracheostomy, Larry could learn to talk again.

Tom was categorically opposed to Larry undergoing this procedure - he did not want his son to have a hole through his throat. Laura was initially silent on the issue, but showed some curiosity toward it within a couple of days. She spent time with a child (in the room next to Larry's) who already had a tracheostomy and she asked nurses and physicians a number of questions about its risks and benefits.

Within a couple of weeks, George once again asked the parents about the tracheostomy. This time they both consented to it. It was performed 'uneventfully' within a week. It took about 4 days for Larry to return to his preoperative state and routines.

A brief afterword to this narrative: Three months following his tracheostomy, Larry's respiratory drive improved and he was able to breath on his own for several hours a day. An additional 2 months later, he was accepted into a special school program where he formed a number of friendships - which he highly enjoyed. Finally, a further 2 months later, Larry's parents learned to manage his complete care and he was discharged home on a home respirator program.

Interpretive Reflections

Horizons of Moral Significance

The stories of Marc and Larry are each unique, each bearing a number of fundamental distinctions. On the other hand, these two very different narratives converge in a number of remarkable ways to highlight significant similarities. The spheres of particularities and similarities (drawing on Walzer's sphere metaphor, 1983) emerge in a dialectical tension.

Although both boys were afflicted with severe disablities, Marc's predicament was particularly distinctive in terms of his extensive mental impairment. This impairment raised concerns among the biomedical staff about his capacities to enjoy life - indeed they believed he was constantly suffering. Marc's parents interpreted his emotional and mental experiences very differently - much more 'positively.' Whereas the parents attributed these differences of view to the intimacy of their relationship with Marc (and the corresponding deeper level of familiarity they had with him), the staff attributed the differences to the parents' psychological denial of reality - their inability to accept Marc's reality. These distinctive viewpoints were rooted in the complexities of understanding the 'inner experiences' of persons with severe mental impairment (which are further complicated among children). Indeed, some literature has discussed some of the difficulties surrounding the notion of suffering in the context of brain injury - but that discussion falls outside the central scope of this thesis.

This difference in views between the parents and staff did not unfold into a sharing and integration of thoughts. Rather, this emerged as a conflictual disagreement whereby each 'side' claimed to have a greater authoritative claim over 'knowing' Marc's experience. The parents' rooted the legitimacy of their claim in their intimacy with Marc, while the staff supported their claims within their professional experience with children like Marc and the psychological responses of parents.

The disagreement was intensified by a number of 'underlying' premises that were not openly recognized. The parents suspected that Marc's affliction was caused by a medical error. It is difficult to know how this suspicion was precipitated (as an insider in the clinical context under discussion, I am working from the premise that the plausibility of such an explanation is extremely unlikely). This suspicion could have resulted from the long period of uncertainty that surrounded Marc's neurological diagnosis and the very foreign and abstract nature of the term 'mitochondrial myopathy.' On the other hand, although this was an unusual case for the clinical staff, it nevertheless 'fit' within their explanatory systems. The medication error explanation was incongruent with the biomedical science paradigm of the latter, and it also cast a shade of fault and accusation upon their professional work.

Additional tension emerged in relation to the medical 'forecasting' of Marc's future. The wide margin of imprecision in the prognostication of Marc's overall condition (for example, early predictions that he would not return home) provided the parents with justifications for questioning other aspects of Marc's prognosis. In particular, they questioned whether his condition was truly degenerative and irreversible. In contrast, the PICU team accepted the prognosis and understood the wide variability of progression as typical of this form of disorder.

As a consequence of the above disparities - the staff interpreting events from their biomedical framework while Marc's parents interpreted contradictions and uncertainties from their framework of suspicion and distrust - both sides became increasingly distanced over time.

An additional sphere of disparity surrounded Marc's case and had foundational significance toward discussions of life-support. Marc's parents had deeply held religious views and felt humans should not voluntarily permit an ending of life. Human life - in any form - held a special sanctity. Also, they held their religious views above their biomedical views and therefore believed that God could transcend biomedical explanations and predictions at any time - they wanted to wait and hope for their miracle. Meanwhile, the biomedical paradigm tends to regard religion as a culture's particular 'beliefs and rituals' (Tambiah, 1990) - a form of understanding subordinate to science (although this is how religion is regarded by the dominant scientific frameworks, I recognize that many biomedical practitioners personally struggle with the significance of religion in their professional work). Here again, authoritative truth claims emerge competitively, with little common ground for reconciliation. Their respective views were mutually rejecting.

Finally, both Maria and John came from traditions where it was considered wrong to 'abandon' sick family members - where family should be present and care for the sick at home. It was apparent that these parents were not speaking in terms of a 'right' to decide for Marc or a 'right' to sustain his life (indeed, this was particularly evident toward the end when Maria wished Marc would die in his sleep). Rather, these parents spoke in a language of duty and obligation. Within their tradition, it was their duty to sustain and care for their loved one. These traditions were inescapably binding. Benjamin Freedman (1996a; 1996b), in his study of Jewish traditions, has examined this notion of duty among adult children of incompetent parents.

> The family members with whom I dealt with... dreaded, rather than welcomed, their involvement in this task. And while they might, in the course of discussion, claim superior knowledge of the patient's wishes and values and judgment of his or her best interests, these claims too did not exhaust the reasons why they demanded decisionmaking authority. At its heart, the claim of these adult children was simple: for them, the duty of rendering medical decisions was continuous with, or an extension of, a general duty upon the family to care for its members who cannot care for themselves (Freedman, 1996a, p.31).

Freedman's argument is consonant with the accounts of Maria and John. For Maria and John, these duties were 'close to the bone' and unquestionable. The duties were shaped by and expressive of their membership in a broader cultural way of life - of being Italian - from which they derived their deeper sense of identity and meaning. They did not feel free to 'opt out' of certain obligations that were particularly difficult - these were all a part of meaningful living. On the other hand, the clinical staff approached Marc and his parents from a professional ethical tradition that required them to be attentive to the parents' concerns and wishes but also (and ultimately) to Marc's best interests - which are typically construed as the proportionate balance of (individualistic) gains and harms related to medical care. The staff also 'felt' an obligation toward Marc. They worked within a professional tradition that assigned great importance to the voice of parents - yet, parental authority was not categorical. The latter was always contestable if it conflicted with a child's best interests - whereby it would be permissible to supplant parental authority (with the support of the courts). However, in light of their disparate views of Marc's inner experiences, it seemed inevitable that they would disagree in their judgement of Marc's current interests. Each side appealed to reputable traditions in their authority claims over what was best for Marc - with scarce common ground for reconciliation.

In contrast, Larry's case involved parental wishes to discontinue life-support. Tom held a consistent view toward a cessation of treatment, while Laura's views fluctuated throughout the course of the narrative. It was remarkable that during the period of intense discussions with specialists, a strong agreement was emerging among professional staff and both parents to end life-support. This raises the question of the potential for ethical dilemmas in the absence of overt conflict: Does the absence of disagreements signify the absence of ethical problems? This was apparently not the case. When confronted with opposition from two partially involved physicians, this opposition enabled the explicit expression of ambivalence by many of the staff (particularly Larry's primary physician) and what appeared to be covert ambivalence within the mother - although she never confirmed this overtly. Until this case was confronted with opposition, the prevailing staff views were in favor of the dominant parent's wishes (in Larry's case, Tom was much more categorical and expressive than Laura). The various agents who were ambivalent, bowed to the father's certainty - not wanting to oppose his parental position.

This period of agreement suggests that staff favor a cooperative relation with parents - particularly when the former hold a view of uncertainty. Also, the various agents held numerous common understandings. There were no disagreements over Larry's diagnosis and the parents accepted medical predictions of his outlook. Indeed, the central problem was not about the truth claims of medical prognostication, but to arrive at the most probable medical prognosis. They accepted the medical determination of the irreversibility of Larry's condition. With hindsight, it became apparent that the forecasts for Larry's course were highly imprecise - yet this was not an area of significant controversy.

A further realm of common views was the central criterion employed for life-support decisions. Both parents and staff valued life but only insofar as it was not disproportionately burdensome. Everyone involved agreed that life-support decisions should be based on the benefits and burdens involved for Larry. The dominant language surrounding this narrative was 'secular' in that there was no appeal to a 'higher good' beyond the individual potentialities of Larry's life. Larry's life was evaluated functionally in terms of the things he would be able to do (in the present and the future) and the suffering he might endure.

The disagreement that ultimately emerged involved a dispute over how much disability was too much. Tom (and all of the specialists consulted in this case) regarded a permanent dependence on a respirator as excessively and cumulatively burdensome. Opposing staff (and possibly the mother), attributed special significance to the fact that Larry was mentally 'normal' and capable of a number of enjoyments. This raises questions about the burdens of life with disabilities. In Marc's case, there was a clear consensus among staff that his state was excessively burdensome - on the basis of his apparent distress but also because of limits in his abilities for experiencing 'normal' pleasures (dependent upon well-functioning mentation). The difficulties involved in judging such inherently subjective phenomena are largely overcome within the adult population by appealing to their (current or previously) expressed wishes. Attempting to judge the satisfactions and sufferings of a child's life poses extraordinary problems.

Indeed, in Larry's narrative, there was a questioning of whether (and how) Larry should have an explicit 'say' in decisions regarding his care. Although legal and bioethical doctrine recognizes the views of the child as important, there has been little published discussion of how to address these in practice. Myra

Bluebond-Langner (1978) conducted a (highly reputed) ethnographic study of 3- to 9-year-old children through their encounters with leukemia. She poignantly voiced the silent experiences of children's struggles with sickness and dying, demonstrating a depth and richness in the children's comprehension that far surpassed the understandings attributed to them by the adults in their lives. Bioethical discourse on the care of seriously ill children will need to address how children ought to participate (practically) in medical decisions.

This comparative study of the cases of Marc and Larry reveals that a discussion of the merits of a particular life is inescapably rooted in the discussants' broader moral outlooks. Engaging in a dispute over who is most knowledgable about what is best for a particular child offers little advance in the care afforded to that child and the moral agency the various caregivers are attempting to enact. Rather (drawing once again on Freedman's notion of duty - which may bear significant relevance beyond the Jewish context within which he articulated it), the central tension is not about who has the highest order right to decide for a child but about the expression of numerous moral obligations rooted in a multitude of moral horizons. These horizons will converge and diverge across the many spheres of moral life - resulting in various forms of agreement and disgreements about what should be done. In light of my earlier discussion of how morality is shaped by the broader horizons of significance from which the various agents enact - moral conflict typically involves a clash of horizons, the confrontation of disparate viewpoints. Richard Zaner has described the clinical context as an encounter of 'multiple voices' that are expressive of different paradigms (Zaner, 1993).

Spheres of Moral Life

The views of the parents of Marc and Larry differed in their conception of the aims of life and familial responsibility. These differences were traced to distinctions in their respective cultural viewpoints. However, in spite of the significance of culture in shaping moral frameworks, remarkable distinctions emerged among agents with similar cultural horizons (for example, between Tom and Laura, or among various professionals working within a shared biomedical paradigm). Although culture is fundamentally formative of moral horizons, moral viewpoints are further elaborated within a cultural community within the realms of its agents' particular histories and context. It is important to guard against an essentialism of culture, wherein we presume the moral views of persons on the basis of their membership in a particular community.

Rather, it seems plausible that additional spheres of human life are determinative of moral views. For example, although both sets of parents expressed importantly different viewpoints, it is noteworthy that (within each couple) the mothers tended to favor more strongly the sustaining of life whereas the fathers spoke more strongly of their concerns about the relative quality of that life. This provides some very limited support for the notion that gender can shape a person's moral outlook, as articulated by Carol Gilligan (1982) and Nel Noddings (1984), among others.

Culture can converge with gender and a number of other potentially relevant spheres of human life (such as age, personal history, or social circumstance) in shaping the moral outlooks of particular persons at particular times. The cases of Marc and Larry have illustrated that moral dilemmas can emerge overtly (and expressed through disagreements) or covertly (nestled within the ambivalences of silent agreements).

A Relational Enactment of Moral Life

The contextual study within this thesis has also illustrated that moral discourse within the clinical encounter is enmeshed within complex relational phenomena.[15] Regardless of the sources of disparate views that emerged within the narratives, these disparities were expressed through struggles for respect, trust, and power.

Respect

Within each disparity, agents sought to have their own views respected. These disparities typically involved insufficient commonalities that could enable a genuinely respectful acceptance of the other. Disagreeing agents lacked an adequate common ground upon which disagreements could be resolved.

This resembles what Charles Taylor has described as the search for (mutual) recognition among interdependent communities. Many (liberal) Western societies have enacted multiculturalist policies and practices that assign freedoms and rights to individuals to conduct their lives according to their own particular outlooks. This legitimizes the expression of differences and the pursuit (by individuals and communities) of equal recognition. An 'ethos of multiculturalism' emerges where persons (and communities) expect an equal recognition of their differences and - in turn - are expected to regard others as equal. This striving for an equal recognition of differences is doomed to fail (according to Taylor) because each agent judges worth in terms of his/her particular moral outlook. These outlooks can be highly divergent and incommensurate. Thus, the pursuit of equal recognition cannot (in many instances) express **genuine** respect.

The case narratives suggest that this striving is comparably apparent within the relationships of the clinical encounter. Patients, families, and clinicans confront an inescapable interdependence, within the context of disparate moral frameworks. In the cases of Marc and Larry, the persons involved were required to discuss and agree upon plans of care that implicated fundamental moral views. These encounters gave rise to ambivalences and disagreements that could be traced to the broader disparities described earlier. These persons struggled to agree on courses of action, while they held significantly different views. Against a background 'ethos of multiculturalism,' this struggle involved a striving (and expectation) among agents to have their particular views respected. Indeed, the discourses that unfolded could be characterized (predominantly) as self-assertions, rather than comparative (rationalist) analyses of rival arguments aiming to arrive at a determination of the child's best interests (as articulated within the dominant model of bioethical discourse). This suggests that the feasibility of successfully discussing and determining what course of action is in the child's best interests - within this context of moral disparities and relational tensions - is highly dubious.

Trust

Disparities also gave rise to 'clashes of intentions' whereby conflicting agents assigned motivational aims toward the other - from their own respective understandings. This contributed to a climate of prejudgment where one person's actions were (mis)interpreted from the disparate viewpoint of the other - resulting in an escalating cascade of silence and distrust.

Richard Zaner (1988; 1991; 1993; 1994), in his phenomenological study of the clinical setting, characterizes this as an 'intimate' encounter among strangers that places the patient in a position of 'unavoidable trust' toward the physician.

In 'ordinary' encounters, trust is a phenomenon that can form between people, on the basis of the quality of their encounters. Trust implies a confidence or a reliance on another - with a corresponding diminution of self-protection.

For a variety of reasons, persons commonly impose limits on the trust that they will have toward someone. These limits can give a person a sense of control over their potential vulnerabilities in an unfamiliar or threatening relationship - or simply express a preference in relational distance.

Each person will also enter a relationship with his/her own personal conditions and checks for giving (or guarding) trust. A person will intensify or diminish his/her trust limits within a particular relationship, depending on how the relationship unfolds.

The clinical encounter involves an obligatory trust relationship that is not subject to the limits, conditions, and checks for trust that are possible in 'ordinary' relationships. Patients and parents are required to confide and rely on strangers for matters that involve deep vulnerabilities - in a manner that circumvents the ways in which people form genuine trust. They are thrust into a position of obligatory trust.

Power

Finally, severe illness gives rise to profound vulnerabilities and dependencies on others. This phenomenon has been well articulated in the literature pertaining to adult patients (Brody, 1992; Cassell, 1985; Katz, 1984; Zaner, 1988; 1994). In the context of children, these dependencies are largely comforted by parents and other family members. However, when the health care required by the child surpasses the family's capacities, the family is required to depend on professional health care. Within the narratives of Marc and Larry, the families were dependent on the PICU staff for addressing most of their sons' critical needs.

Consequently, these families were also faced with limitations in their control over the care their children received. They were required to seek the cooperation of the staff in enacting particular forms of care. These parents were enmeshed in a subordinate power relationship with the PICU staff, with regard to their sons' care.

The PICU staff might likely argue that they too are in a subordinate power relationship with the parents, given that laws heavily favor parental preference in medical decision-making - requiring staff to seek the cooperation of parents (a matter of particular significance in situations when parents want things that the staff diagree with).

However, although both sides may struggle with forms of powerlessness, the parents are particularly disempowered by the asymetry inherent in their relationship with the staff - in terms of specialized knowledge, skills, control over critical resources, and the power resulting from these.

Thus, parent-staff relations inherently involve a power dimension. This was particularly apparent in the narratives when agents engaged in competitive truth claims over who had the most authoritative understanding of what was best for the child. The disparities in moral views (described above) contributed further to these power conflicts (given that these disparities presented scarce options for reconciliation), whereby the respective agents struggled to establish the dominance of their paradigm (with the staff holding the privileged position of the prevailing power of the scientific paradigm within Western culture as well as control over biomedical care).

Therefore, the actions of parents need to be interpreted in terms of this subordinate position - which may shape the type of things they will feel free to express and do (as was the case with the various silences the parents enagaged in throughout the narratives). This resulting silence further complicates the genuineness of the moral discourse that can be achieved.

Summary

In summary, the medical encounter can give rise to tensions among the disparate moral frameworks of the persons involved. This is further complicated by (that is, contributes to and is expressive of) relational tensions involving respect, trust, and power.

Having argued at length for a thick framework for bioethics, I will conclude with a discussion of what this implies for bioethical practice and decision making.

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Implications for Bioethical Practice

Early in this thesis, I outlined a number of fundamental problems inherent in the dominant paradigm of bioethics - a paradigm centred (largely) on legalism. This dominant model is mistakenly premised on an universalist (ethnocentric) moral framework. I argued for a shift toward a moral viewpoint grounded in cultural context. This involves a recognition that moral frameworks are shaped by cultural horizons.

Within the clinical setting, this construes ethical dilemmas as a 'collision' of disparate moral views. In light of the contextually rich nature of moral life, I proposed an interpretive framework for the practice of bioethics - an approach that undertakes thick description and interpretation of clinical encounters. I illustrated what a thick bioethics could look like by engaging this approach toward the cases of Marc and Larry.

This contextual analysis suggested that moral dilemmas within the clinical encounter involve conflict between disparate moral viewpoints - viewpoints that are broadly shaped by culture and specifically elaborated by particular contexts. Also, the narratives of Marc and Larry demonstrated that moral discourse involves a relational enactment - the negotiation of moral views is transacted within the 'politics' of relationships. The relational phenomena of respect, trust, and power emerged as social tensions resulting from, and constitutive of, moral conflict.

I have also argued that the practice of bioethics consists of more than 'just' describing and interpreting cases thickly. Rather, bioethics involves a further effort toward the resolution of ethical dilemmas. Within the moral framework of this thesis, I have described this as a mediational work. The bioethicist seeks to reconcile conflicts among the multiple voices in the clinical encounter by seeking to 'fuse' the disparate moral views.

This draws on mediational process - beginning with an identification of some common ground (and common language) - for example, the conflicting agents could come to agree that they all (a) want what is best for the child, (b) wish to comfort the child's suffering - and then seek to elaborate what each means by 'best' and 'suffering' - and so on.[16]

This study has demonstrated that the bioethicist undertaking this mediational work should also be attuned to the complex relational phenomena related to this discourse.

In the narratives of Marc and Larry, various agents attempted to perform this mediational work (chiefly, myself for Marc's case, and George for Larry's case). These efforts enabled some resolutions (yet unravelled some further conflicts).

The clinical encounter could be enriched through the engagement of a bioethicist practicing from a thick (interpretivist) framework. A thick bioethics requires immersion in the particulars of a case. The bioethicist would attend the various team meetings, but also seek enagagement with patients and families in pursuit of 'silent voices among the vulnerable.'

The early stages of Larry's case demonstrated that the absence of a disagreement does not necessarily correspond with an absence of an ethical dilemma. Although a thick bioethics is centred on context, this should not necessitate a slide toward extreme relativism. Rather, the bioethicist serves as a liaison with the broader (legal, medical, and bioethical) norms that may be relevant to the case at hand.

For example, although Larry's parents and PICU caregivers may have reached an agreement to discontinue life-support, a consulting bioethicist would have likely challenged this decision on the basis of the legal and bioethical 'best interests' doctrine I outlined earlier (indeed, the hospital ethicist did in fact raise a number of objections when Larry's case was discussed in the PICU ethics meeting I described in the narrative). Given that most persons involved with Larry indicated that his life involved some significant enjoyments (and if asked, he would likely wish to continue living), the ending of life-support would not serve his (current) best interests.

A bioethicist (with a comprehensive knowledge of the relevant legal, professional, and bioethical norms) should seek to ensure that clinical practices conform with the recognized doctrine. This doctrine could serve as 'minimalist' moral views that are necessary but not sufficient for ethical care. The bioethicist aims to ensure that this minimalism is respected across cases, while seeking to ground the moral discourse of a specific case within the maximalist particularities of that local context.

I envisage a practice that resembles that of a mediator engaged in the resolution of a marital breakdown. The mediator recognizes that the separating adults can freely choose from a wide range of possible forms of independent life - yet the former will intervene to ensure that some minimal (legally sanctioned) conditions are respected regarding the interests of (vulnerable) children.

A thick bioethics involves a recognition that there is no consensus on the ultimate goods that the clinical encounter should pursue. Ethical care of critically ill children requires a 'rapprochement' of the various moral voices speaking for the child - the parents, physicians, nurses, other professionals, the state, and the children themselves. The bioethicist seeks to reconcile the disparate (particular) views of these many agents - in a manner that is congruent with widely-accepted (universal) views - with an attunement to the relational dimensions of moral life.

> Clinical ethics is a disciplined way of helping people understand their conditions, situations, and prospects by helping them (at times, unfortunately, insisting that they) grapple with their own moral beliefs, what they really and truly want and believe is worthwhile.... The clinical ethicist works within this nest of relationships - which sometimes fairly bristle with thorny contention - among people in specific place and circumstances and within the context of rules, policies, laws, and protocols hopefully to achieve some coherence to lives that threaten to shatter.
> From Richard M. Zaner, (1993). Troubled voices: Stories of ethics and illness. Cleveland: Pilgrim Press. p.xxi.

Notes

(1) For the purposes of this thesis, my references to 'medicine' do not refer exclusively to the work of physicians. Rather, I am referring to the biomedical paradigm that dominates modern Western (professional) health care. Therefore, 'medical' also refers to additional professionals working within this framework - such as nurses and various technologists.

(2) At the time this research was conducted, I was the head nurse of the pediatric intensive care unit where this study was conducted. I had been head nurse there for 10 years, and had worked in this unit for a total of 17 years. My role as head nurse implicated me directly and indirectly in particular cases. My involvement varied from case to case - depending on what I could offer to the circumstances of each situation. The reader will note that my involvement with one of the following cases (Marc) was predominantly direct, while my role in the second case (Larry) was largely indirect.

(3) In their discussion of the best interests standard in the care of infants, Buchanan and Brock further elaborate that infants have two types of interests: current interests and forward-looking (future-oriented) interests.

> The current interests of infants are exclusively experiential and functional: They are interests in achieving pleasure and in avoiding pain and discomfort, as well as interests in maintaining organic functions.... Developmental interests are especially prominent among the forward-looking interests of the infant. Developmental interests

> are of several sorts, the most important being what may be called (1) agency development interests, (2) opportunity interests, and (3) human relationship interests (Buchanan & Brock, 1990, p.247).

(4) I recognize that the 'sanctity of life' and 'respect for autonomous choice' principles are not necessarily irreconcilable. Indeed, much of the legal doctrine and jurisprudence I refer to in this discussion strive to reconcile these principles. For example, most of the legal sources I cite that support the sanctity of life, typically elaborate that the value of life is not absolute. Rather, they regard the value of a life in relation to the patient's expressed wishes and the quality of that life.

(5) A number of additional critiques have been articulated regarding the dominant framework of bioethics, that are not as directly problematic for the cases presented in this study. These include criticisms that bioethics: (a) relies excessively on a framework of 'principlism' (I elaborate this criticism in the next note); (b) mistakenly presumes that moral problems can be analyzed through 'deductivist' reasoning (DeGrazia, 1992; Duff, 1987; Jonsen and Toulmin, 1988; Murray, 1987); and (c) is premised on an 'applied ethics' moral framework that is impervious to the particulars of moral life (Carson, 1990; Hoffmaster, 1991; Jonsen & Toulmin, 1988; MacIntyre, 1984; Toulmin, 1982).

(6) Beauchamp and Childress' four-principle approach (1994) has been criticised for: (a) being too

general and vague to apply to concrete situations; (b) not specifying a practical way of resolving conflicts among moral principles; (c) relying on a rationalist orientation that implicitly shapes the content of moral discourse; (d) inadequately recognizing the context of moral problems; (e) presuming that the specified principles represent universal moral ideals, rather than particular points of view; (f) failing to provide a central theory of justification that ties the principles together; (g) offering little more than a simple checklist of principles, that lack deeper moral substance; and (h) relying on a process of interpretation that ultimately amounts to a simple form of inductive intuitionism (Clouser & Gert, 1990; DeGrazia, 1992; Hoffmaster, 1990; 1992; DuBose, Hamel, & O'Connell, 1994; Kennedy Institute of Ethics Journal, 1995; Maclean, 1993; Toulmin, 1981).

(7) I recognize that alternative conceptions of ethnography have been articulated within anthropology - that Clifford Geertz's views are not universally held within that discipline. I have chosen to highlight Geertz's ideas because: (a) his work is highly acclaimed within anthropology as well as by other disciplines, and (b) his ideas have been directly related to moral discourse both within anthropology and moral philosophy.

(8) Within the limited space that I have allocated for this comparison, I have summarized the principal conclusions of these two ethnographies in an attempt to

illustrate two divergent moral frameworks within ethnographic accounting. I recognize that the detail I can provide is too limited to enable the reader to form his/her own interpretations of the practices examined, which is beyond the scope of this thesis.

(9) Rosaldo maps out a dense topography of Ilongot language and emotions. The pluralist significance of the heart is traced and related to the notions of 'liget' (a word suggesting energy, anger, passion) and 'beya' (or knowledge). These notions are central to the Ilongot conception of life cycle and development of the self. Headhunting, practiced by youthful bachelors, is reported to relieve a state of 'heaviness' in the youthful heart. Elders are regarded as necessary in the hunt, helping the youths 'keep their liget high and their hearts focused.' Headhunting is rooted in an interrelation of tradition and authority: "Youths say they kill because their 'fathers' have" (p.147), while "the unruliness of youths becomes a resource in adult political life" (p.147), legitimizing adult claims to authority.

(10) Rosaldo states, early in her monograph,

> To know what Ilongots meant in declaring that the wishes of their hearts led them to kill required a grasp of words like 'heart' and 'anger' as they were used in a variety of different contexts. To understand the order in Ilongot social lives, I had to hear what was implied by the things Ilongots said, and in particular, to 'interpret' or discover the broad sorts of concerns that lay behind their explanations of their acts. Whereas other anthropologists have been inclined to work 'from

> outside in,' first describing a patterned social world and then asking how individuals are 'socialized' to work and live within it, I found it more illuminating to begin from the other pole of the analytical dialectic and ask how personal and affective life, itself 'socially constructed,' is actualized in and orders the shapes of social action over time (p.19-20).

(11) Within her framework, Boddy argues "that what I sought lay not so much behind my informants' statements as in them, and not so much in Islam as, so to speak, in front of it" (p.7). She seeks to 'look beyond' informant statements, which are constrained by local power relations.

(12) This problem is particularly apparent in some of Albert Jonsen's work (1991). In his explication of methodological techniques for casuistry, he demonstrates a strong preoccupation with the adoption of rules and maxims that can be applied across contexts, limiting the contextual orientation of his view of casuistry. Jonsen asserts that "The work of casuistry is to determine which maxim should rule the case and to what extent" (p.298). Also, he argues for a taxonomy of cases that involves a "lining up of cases in a certain order" (p.301).

(13) In the French version of the abstract for this thesis, I have used hermeneutics as a term for interpretivism because the former is more readily recognized in that language.

(14) Portions of these narratives, that are not fundamentally relevant to the central concerns of this

thesis, have been modified in an attempt to preserve the anonymity of the persons involved. For example, all of the names presented are pseudonyms.

(15) This is congruent with the findings of Kaufert and O'Neil's (1990) study of informed consent among Native Canadians (which I described earlier) wherein they identified social tensions between clinicians and patients involving conflicts over trust and power.

(16) Mediation has received some attention in the bioethical literature. This has related largely to mediational strategies that hospital ethics committees can employ to address disputes arising between professionals and patients and their families. West and Gibson (1992) examined the work of 20 American medical ethics committees and found that these committees were very interested in the use of mediation, and that many committee members were already using mediation process in an informal manner. The limited amount of study in this area suggests mediational models can enhance bioethical practice (Craig, 1996; Drane & Coulehan, 1995; Fleischman & Murray, 1983; West, 1992). However, these works rest largely on a conflict resolution framework that aims to reconcile disputes over competing rights. Mediation is proposed as a minimalist model that frames the dilemma as a conflict among some central norms, principles, and laws. In contrast, the maximalist framework that I am proposing is morally richer because

it enables the bioethicist to examine the norms, principles, and laws themselves as potential sources of conflict, within a detailed contextual analysis of the moral goods at issue.

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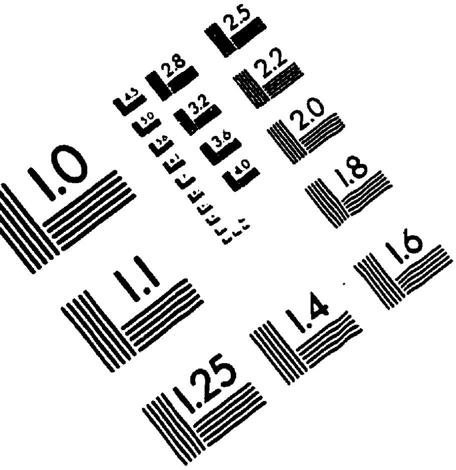

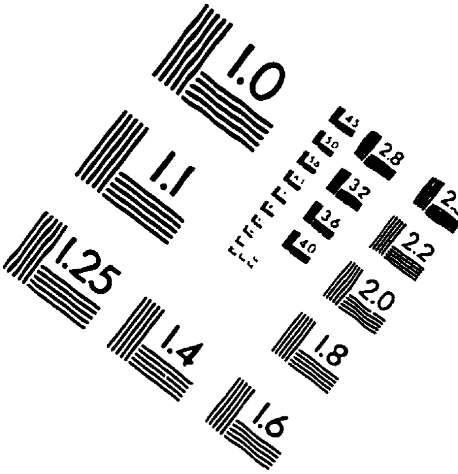

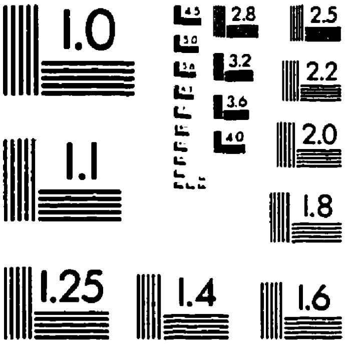

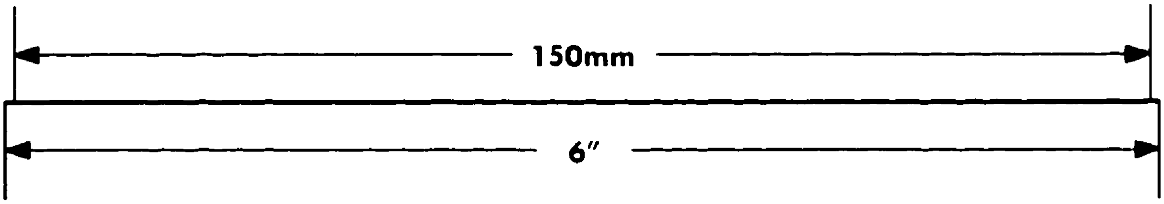

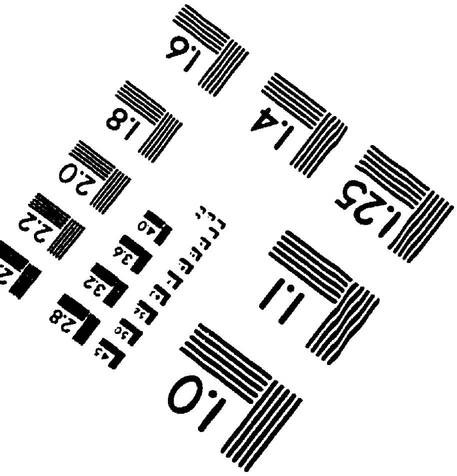

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