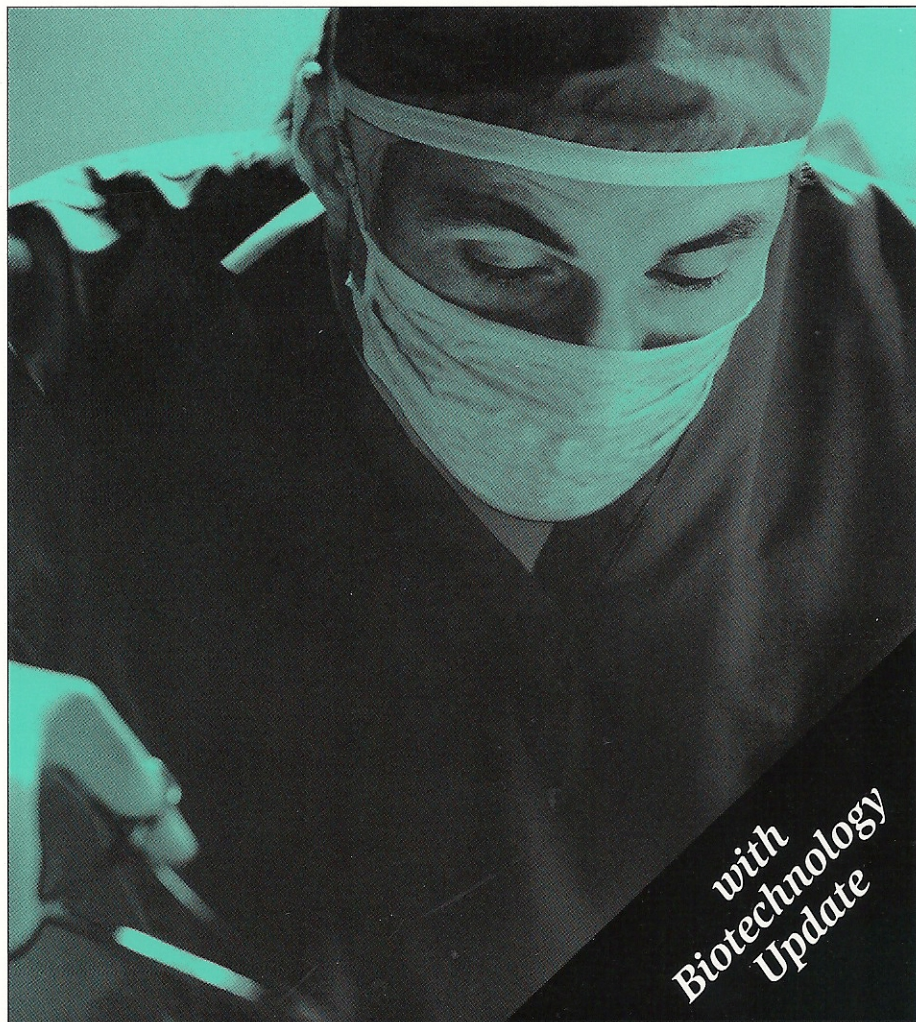


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GUEST COMMENTARY

## FROM STEINEM TO SCHLAFLY: CREATING A BASIS FOR CONSTRUCTIVE CONVERSATION ON HUMAN SEXUALITY

MARY B. ADAM, M.D.

Sex seems to be the topic of the day. You read about it in magazines from *Science* to *People Magazine*. It's on all the TV talk shows. Yet it is obvious that people hold different views on human sexuality. How can we promote constructive conversation on human sexuality among people who hold such radically opposing views, especially in regard to monogamy, abstinence and marriage?

One's worldview fundamentally alters one's understanding of human sexuality in terms of monogamy, abstinence and marriage. When we care enough to really understand another's belief system, however well articulated or consciously held that system may be, we reduce the polarizing effect that these kinds of debates often engender. Understanding worldview allows the speaker or listener to ascertain the basic assumptions that form these various views of human sexuality. It allows one to identify an area of common ground from which to continue the discussion as well as help identify irreconcilable differences.

In the past, human sexuality has been discussed primarily from a developmental, sociological or psychological model. These models, while cognitively helpful, are limited in trying to influence communication on human sexuality because they each represent a piece of the picture. Sexuality is an essential part of being human. However, each of us views our own sexual nature in terms of our own worldview. Worldview has been defined simply as "a comprehensive way of looking at how the world should function."<sup>1</sup> To completely understand a person's worldview we would have to ask him or her answer the following questions:

*What is the origin of man?*

*How was man created?*

*Is there purpose in life?*

*Why do I exist?*

*Why is there evil?*<sup>1</sup>

While obviously it is inappropriate to fire these kinds of questions at those we don't know well, one can get a sense of a common worldview by tuning into popular culture. Daytime talk shows, music, and newspapers all give us a glimpse into how people think and function in the world around us.

Understanding worldview also gives a context within which to understand the meaning of words. It is analogous to the advantage one has if one understands Latin. The study of Latin brings an added dimension to one's understanding of the English language because Latin gives insight into the roots or foundations of word meaning. The study of worldview brings an added dimension to understanding concepts like freedom and "responsibility." These words can have very different meanings when used within the context of a particular worldview. For example from one perspective, freedom may mean the freedom to do what I want. Whereas to someone with another worldview, freedom may mean the opportunity to do what is right.

Many concepts such as freedom, responsibility, and even abstinence have become ambiguous terms in discussions about sexuality. This ambiguity is evidenced in our culture's move from a modern to a postmodern view of man. What does the cultural move toward postmodernism mean and how does it widen the gap between the traditional Judeo-Christian thought and present day views of human sexuality. A brief overview of western thought is helpful in beginning to look for answers.

The pre-modern phase of Western civilization is characterized by people who believed in the supernatural. God or gods gave life its meaning. The spiritual world was supreme and the acts of the gods caused things to happen on earth. This phase was not characterized by a single monolithic worldview but rather was a complex dynamic era that included mythological paganism, classical rationalism, and Biblical revelation. Greek society at this time was an uneasy mixture of pagan mythology and classical rationalism. Plato explored the ideals and universals of the mind. Aristotle investigated the tangible universe by classifying plants and animals and unveiling the purposes of physical objects. Plato and Aristotle made significant contributions to Greek culture. Yet this culture was no utopia, but rather was morally decadent. Greek society institutionalized infanticide, slavery, war, oppression, prostitution, and homosexuality. At this stage of civilization there was general agreement that the spiritual realm contained the source of all values and the true destiny of human beings. Neither humans or society or nature was autonomous, but all were utterly dependent on the sovereignty of God.

The modern age of Western civilization marked a shift in thinking with a rejection of the supernatural. The natural world was all there was and it could be understood and explained through our five senses. Mathematics and science would allow exploration of the world and a comprehensive understanding of all that existed. Human reason was capable of solving all human problems and society was remade along the lines of scientific rational truth. Confidence in science meant there was confidence in objective order and knowable absolutes. The rights of man were exalted. Darwin's theory of evolution allowed for a rational explanation of the world without the supernatural. Nature became self contained and science could explain everything. The social sciences were

invented to explain human institutions and psychology sought to explain the inner life of the mind, all in terms of a closed system accessible to empirical scientific methods. However, Darwin's theory destroyed the perception that nature was harmonious, and replaced that perception with 'survival of the fittest', a raw struggle where the strong prey upon the weak in order to allow their species to propagate. Such stark naturalism was hard to live with and twentieth century society began to seek meaning apart from the material world.

The postmodern age of Western civilization was described as a reaction to a material world devoid of meaning. Individuals or social groups create meaning for themselves by their free choices and deliberate actions. Each individual or social group determines their own meaning, truth, and moral values. Pluralism or multiple equally valid narratives were used to explain man. In the absence of absolute truth, tolerance became the greatest virtue. G. Veith has summarized the postmodern age in the following way:

*What I want and what I choose is not only true (for me) but right (for me). That different people want and choose different things means that truth and morality are relative, but "I have a right" to my desires. Conversely, "no one has the right" to criticize my desires and choice.<sup>2</sup>*

Veith's statement illustrates the difficulty in defining postmodernism yet identifies its essence. In postmodern thought, absolute truth and moral judgments are seen as a matter of preference. The postmodernist's emphasis on relativism would significantly affect their answers to the questions 'what is man' and 'how is human sexuality to be understood?' The following section will address these two questions; 'what is man' and 'how is human sexuality to be understood' from the perspectives of various worldviews.

## Postmodernism

Postmodernism sees man as being determined by his will and emotions as opposed to his reason and his intellect. Reality is more of a social construct. There is no grand story that describes who human beings are, no author or creator. Instead meaning is created by the individual or social group. Man is liberated when he rebels against oppressive notions of knowledge and truth. Moral guidelines are often believed to be masks for oppressive power. Moral absolutes have been shelved in favor of relativism. For the postmodern, morality is simply a matter of desire. "I will choose what is right for me, you choose what is right for you" or "whatever" are, in effect, the campaign slogans for postmodernism. In the postmodern paradigm, human sexuality is what you make it. The fulfillment of sexual desires is viewed as a right. Since human sexuality is a preference, all forms of sexual expression are viewed as equally valid. Cultural mores or judgments regarding sexual expression are viewed as opinions instead of absolute standards. Sex is seen as a private matter that is not open to societal judgment. Judgment is seen as the antithesis of tolerance and pluralism. Repression of sexual freedom for any reason is negative. Tolerance of any given individual's idea of sexual expression is seen as good. This allows the individual freedom to define his or her own idea of sexuality and the way

that it should be expressed. Taken to its logical conclusion, tolerance in the area of human sexuality means that there is no difference between homosexual and heterosexual expression. Sex is no longer tied to procreation because through technology freedom to be sexually involved without the burden of pregnancy has been achieved. Sex should be enjoyed without having any strings attached. The independence of partners is valued and multiple partners is seen as the norm. Lifelong monogamy is seen as abnormal.

## **Feminism**

Feminism is in many respects a sub class of postmodernism. Feminism is rooted in the view that women need to be liberated from male domination and oppression. Gloria Steinem, a founding mother of feminism has stated it this way:

*But now we know we can topple hierarchies by starting with our bodies. After all, male dominant, racist and other unjust systems must control female bodies as the most basic means of production, the means of reproduction, in order to "own" children through systems of legitimacy, to decide how many workers and soldiers the nation needs, and to maintain the degree of race (and class) "purity" that keeps hierarchical systems going.<sup>3</sup>*

In the feminist paradigm human beings are independent of a transcendent being. The narrative by which one understands the relationship of human beings is that of male oppression of women. In this context, feminism views human sexuality through the twin concepts of power and choice. Exercising power almost demands becoming sexually active. A woman who becomes sexually active discovers her power over men and supposedly can use it to enhance her life and choices:

*There have always been those who have stood in the way of our exercising our rights, who tried to restrict our choices. There probably always will be. But we who have been oppressed should not be swayed in our opposition to tyranny of any kind, especially attempts to take away our reproductive freedom.<sup>3</sup>*

Exercising power and maintaining reproductive freedom allows feminists to redefine the whole notion of virginity. The 1992 edition of *Our Bodies, Ourselves* states:

*It might be helpful to think of virginity differently. Instead of virginity being something we 'lose' or 'save' for someone, it could mean our physical, spiritual and emotional wholeness, our self-respect and bodily integrity, our freedom to make a choice. When we make choices about sex out of this feeling of self-respect and virginity, we will more likely put ourselves into situations we can be glad about.<sup>4</sup>*

This freedom to choose includes a freedom to choose different sexual partners and the freedom to choose when and if to have children. Lifelong monogamy is not to be expected.



## Naturalism

Life long monogamy is not the expected norm from the naturalistic point of view, either, however the reasons are different. A naturalistic worldview sees man as a complex life form that evolved, independently of a creator or designer. The naturalistic view of man has led to a naturalistic view of human sexuality. Sex is viewed as a natural human instinct necessary for the propagation of the species. Fulfillment of sexual desire can be accomplished without any feelings of love or specific commitment to one's sexual partner. Sex is required for the propagation of the species, but marriage or lifelong monogamy is not. The September 1998 issue of *Science* in a special section discussing *The Evolution of Sex*, contained an article entitled *A New Look at Monogamy* by Virginia Morrell who states:

*Social monogamy, in which parents cooperate to raise their brood, is relatively common among animals-but true sexual fidelity is not. Does this body of research on animal promiscuity offer insight into human behavior? As anyone who has listened to country music knows humans are more like bluebirds [where on average 15-20% of the chicks are not sired by the male in the partnership] than the faithful California mouse." ...Still most researchers agree that, as Sarah Hrdy, an anthropologist at the University of California, Davis, puts it, human "mothers evolved needing help with rearing the kids." Thus social monogamy, at least was evolutionarily favored.<sup>5</sup>*

Social monogamy, as opposed to true sexual fidelity or genetic monogamy, is seen as the norm. True sexual fidelity has no beneficial impact unless the negative effects of Sexually Transmitted Diseases (STD), contracted because of exposure to multiple sexual partners, diminishes ones ability to get their genes into as many offspring as possible.

Human sexuality is seen as having both reproductive and recreational aspects. Current genetic technology even allows for a complete separation of sexual reproduction and sexual recreation, and this can be used for benefit of the human gene pool. Survival of the fittest requires utilizing this ability to optimize the genetic potential of the species. In fact, the case for the aggressive controlled management of the human gene pool, a logical extension of naturalism, has been made by Joseph Fletcher, the founder of situational ethics who states:

*Lovemaking has a two dimensional nature, procreation and recreation. On its procreative side sex should be well controlled, a discipline of careful calculation, whether it is carried out naturally or artificially. On its recreative side, spontaneity and personal feeling should reign.<sup>6</sup>*

Prior to advances in reproductive technology, a naturalistic worldview would have required an emphasis on the reproductive versus the recreational aspects of sex. This would have eliminated homosexuality as a form of sexual expression because there would be no perpetuation of the species. However, with the technology to completely separate sex into procreation and recreational components, homosexual expression no longer represent genetic elimination.

Yet, STDs, which can have negative, even fatal impact on newborns, continue to present a problem for survival.

“Survival of the fittest” was not exactly what God had in mind when He created man according to the Judeo-Christian view. This view sees man as the pinnacle of creation. God created man and woman in His own image and stated that His creation was good (Genesis 1:31). God not only made man but gave him dominion over all other living things. God created human sexuality and said it was good. Sexual intercourse was ordained by God for both procreation (Gen1:26-28) and for the intimacy and closeness of the couple (Gen. 2:18-25). This gift of sexuality was to be opened within the context of marriage and marriage only. The New Testament discusses sexual desire as an appropriate reason for marriage (1 Cor. 7), and clearly teaches that the sexual union is to be confined to husband and wife for life. Adultery and fornication are condemned and chastity is commanded. C. S. Lewis describes chastity in the following forthright manner:

*Chastity is the most unpopular of the Christian virtues. There is no getting away from it: the old Christian rule is, “Either marriage, with complete faithfulness to your partner, or else total abstinence.” Now this is so difficult and so contrary to our instincts, that obviously either Christianity is wrong or our sexual instinct, as it now is, has gone wrong. One or the other. Of course being a Christian, I think it is the instinct which has gone wrong.<sup>7</sup>*

Other writers have described the Christian view of human sexuality this way: “From a Christian perspective, sexuality is a wonderful gift from God intended for physical pleasure, emotional support, and spiritual unity.”<sup>8</sup> In the Judeo-Christian worldview lifelong monogamy would be the norm. Homosexual expression would be considered a deviation from expected standards because it did not fit the pattern of one man and one woman.

These different worldviews represent the overall way people think, the belief system that influences how they see life as a whole. Worldview dramatically affects ones approach to human sexuality. For example, lifelong monogamous marriage would be acceptable under a postmodern framework as a personal choice but not as an expected moral action. But the proscription of abstinence as the “right” action for all people would be seen as intolerant and therefore untenable. Right actions do not exist objectively but rather are decided upon by individuals or groups.

From a naturalistic view, abstinence until marriage and fidelity within marriage would be acceptable but in no way would it be required. A naturalistic worldview sees morality as behavior patterns chosen by natural selection because those behavior patterns enhance survival. A naturalistic view of “moral choices” reduces morality to a description of human behavior but gives no foundation for the prescriptive nature of morality—the oughtness. Beckwith and Koukl describe it as follows:

*When morality is reduced to patterns of behavior chosen by natural selection for the survival value, then morality is not explained it's denied. . . . Evolutionists. . . are ultimately forced to admit that what we think of*

*as higher truth of morality turns out to be a shameless ploy of nature, a description of animal behavior conditioned by the environment for survival. We've given conduct a label, they argue: morality. But they say there is no real right or wrong.*<sup>9</sup>

On the other hand, from a feminist perspective, required moral choices are the result of oppression by white males. Required sexual abstinence before marriage and lifelong monogamy would be an oppressive and unacceptable limitation on a woman's reproductive freedom. In fact sexual abstinence carries an entirely different meaning for a feminist than it would for a Judeo-Christian, according to the 1992 edition of *Our Bodies, Ourselves*.

*There is nothing wrong with abstinence. In fact, sometimes it is just what we want. Abstinence means making love without having sexual intercourse. It is the most effective form of birth control, has been used for centuries and is still very common. It has no physical side effects as long as prolonged sexual arousal is followed by orgasm to relieve pelvic congestion.*<sup>4</sup>

Again the importance of defining terms before making judgments is seen.

These varied understandings of human sexuality and their corresponding definitions of sexual abstinence have found their way into sexual abstinence programs or curricula. Two examples of abstinence only sex education curricula are *FACTS*<sup>10</sup> and *Managing Pressures Before Marriage*.<sup>11</sup> *FACTS* defines abstinence as "refraining from the act of sexual intercourse and all the intimate physical acts which lead up to it including touching underneath clothing." *Managing Pressures Before Marriage* defines abstinence as "no sexual intercourse, other methods of expressing physical affection are OK." Thus even with in the "abstinence only" curricula understanding worldview is essential in order to understand what is meant by sexual abstinence. Irreconcilable differences in the basic understanding of words like sexual abstinence abound.

Words like "freedom" and "responsibility" also have different meanings when understood through the lens of different worldviews. Freedom in a Judeo-Christian view would mean freedom to do what is right. Freedom from a postmodern perspective would mean freedom to do what I want. Responsibility in a Judeo-Christian view means responsibility for my actions to God and others. It implies that there is an external standard by which one's actions will be judged. Responsibility from a postmodern or naturalistic view means responsibility to self. "Survival of the fittest", the ultimate in responsibility to self, doesn't require one to leave much room for the weak, the sick, the injured, yet a Judeo-Christian worldview would command attention to those in need.

Given these irreconcilable differences is it even conceivable that Gloria Steinem, a founding mother of feminism and Phylis Schlafly, founder of Eagle Forum, a conservative anti-feminist parent rights group could ever have a constructive conversation on human sexuality? If so where would it begin, how would it start? It would begin with each woman taking the time to truly understand each other's perspective. In our own lives it begins when we attempt to comprehend what other people really mean when they use words like abstinence and monogamy. It begins when we put down our passionately held convictions long enough to hear what those with opposing viewpoints are

really saying. It's easy to converse with a person: it's hard to converse with an ideology. When we really understand the worldview that shapes an individual's predilections and behavior, we are much more likely to communicate, with clarity and compassion, our own faith in a God whose righteous standards are meant to lead us into true freedom. E&M

## Endnotes

1. Ted Baehr, *The Media Wise Family* (Colorado Springs, Colorado: Chariot Victor Publishing, 1998), 247-258.
2. Gene Edward Veith, Jr., *Postmodern Times: A Christian Guide to Contemporary Thought and Culture* (Wheaton, Illinois: Crossway Books, 1999), 195-196.
3. The Boston Women's Health Book Collective: *Our Bodies, Ourselves for the New Century* (Boston, Massachusetts: Simon and Schuster, 1998), 17, 414.
4. The Boston Women's Health Book Collective: *Our Bodies, Ourselves for the New Century* (Boston, Massachusetts: Simon and Schuster, 1992), 213, 279.
5. V. Morrell, "A New Look at Monogamy," *Science*, (1998): 281, 1982-1983.
6. Joseph F. Fletcher, *The Ethics of Genetic Control* (Buffalo, New York: Prometheus Books, 1988), 175.
7. C. S. Lewis, *Mere Christianity* (New York, New York: Simon and Schuster, 1943), 90.
8. G. Stewart, et al., *Basic Questions on Sexuality and Reproductive Technology* (Grand Rapids, Michigan: Kregel Publications, 1998), 20.
9. Francis Beckwith and G. Koukl, *Relativism: Feet Firmly Planted in Mid-Air* (Grand Rapids, Michigan: Baker Books, 1999), 161.
10. R. Fuller and J. McLaughlin, *I'm in Charge of the FACTS: A Comprehensive Prevention Curricula for Junior High Students* (Portland, Oregon: Northwest Family Services, 1998).
11. M. Howard, *Managing Pressures Before Marriage* (Atlanta, Georgia: Adolescent Reproductive Health Center, Grady Health System, 1997).

# THE FAILURE OF FORMAL RIGHTS AND EQUALITY IN THE CLINIC: A CRITIQUE OF BIOETHICS

CHLOË G. K. ATKINS, PH.D.

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## Abstract

For communities which espouse egalitarian principles, the hierarchical nature of care-giving relationships poses an extraordinary challenge. Patients' accounts of their illnesses and of their medical care capture the latent tension which exists between notional, political equality and the need for dependency on care from others. I believe that the power imbalance in doctor-patient relationships has broad implications for liberal democracies. Professional and care-giving relationships almost always consist of an imbalance of knowledge and expertise which no template of egalitarian moralism can suppress. When we seek help or guidance from authority figures, we are at a disadvantage politically even though we may be equal citizens theoretically and legally. Hierarchic relationships persist within democracies. Moreover, they tend to exist within a realm of privacy which is only partially visible from the social realm. In the end, traditional notions of liberal autonomy and egalitarianism do not properly describe or monitor these interactions. Liberal rhetoric (i.e. terms such as equality, rights, consent, etc.) pervades much of bioethical literature and interventions but, this very language tends to mask the persistence of structural hierarchies in the clinic. The doctor-patient relationship forces democratic communities to confront the problem of continuing hierarchic power relations and challenges liberalism to revise its understanding of individual autonomies.

**Keywords:** *Bioethics, Liberalism, Equality, Feminism, Illness Narratives, Narrative, Medical Record, Politics, Medical Culture*

## Introduction

During the last two decades, I have not only been a patient on numerous occasions but, as part of my academic research I have also undertaken an ongoing review of patients' narratives about their journeys through illness and through their medical treatments. In general, these stories are imbued with a sense of spiritual longing and exploration. The more modern accounts, however, also express a frustration with the culture of medicine, along with an abiding

sense of powerlessness that seems to accompany medical care. Consequently, this paper uses these narratives' to launch a discussion of the peculiar political disposition of patienthood.

In an effort to more fully explicate and contextualize the distinctive nature of patients' impotence, it contrasts patients' stories with an analysis of the evolution of clinical culture during the last 150 years. Michel Foucault's archaeology of the clinic provides a base from which I launch this critique. By examining medicine's progression as an objective science and by dissecting the manner in which it assesses and describes patients in its own clinical narrative (i.e., the medical record or chart), this paper depicts the various cultural and structural elements which undercut patients' sense of autonomy and equality in the medical environment.

That patients feel unequal and overlooked while receiving medical care is not a novel revelation. In fact, the discipline of biomedical ethics, or bioethics, arose over two decades ago to combat the latent paternalism of the hospital. To some extent, bioethics has emerged as a means of facilitating patients who, having lived in liberal democracies and are imbued with a rhetoric of rights, equality, liberty and autonomy, consequently challenge the historical and pervasive view that 'doctors know best' when individuals become ill. During the twentieth century, the normative standard that all persons are equal not only becomes increasingly embodied in statutory regulation at the state level but also finds its way into clinical practice under the guise of "patients' bills of rights" as well as in health policy initiatives which aim at "client-centred care." I argue that despite the formal equality that is entrenched in democratic communities and in clinical codes of conduct, patients find that they are less than truly equal when they enter the clinic. Thus the modern, western patient harbours an expectation of equality which is often frustrated by the prevailing culture and practices of medicine. Politically, patients experience a discordance between their perception of themselves as equal citizens and their submission to the objective observation and discourse of the clinic.

Accordingly, many bioethicists would argue that bioethics does in fact deal with the problem of inequality and autonomy. Here they would point to the numerous ethics committees which meet to discuss clinical practices and which look at individual cases in order to guide clinical decision-making. Moreover, they might argue, it is in the assessment of each case that a patient's voice is not only heard, but valued—for ethically-minded clinicians listen to case studies and try to match the particulars of these scenarios with appropriate ethical principles. In this construct, bioethics attempts to mediate the tension between patients' observations and those of the medical record. Moreover, the discipline encourages the penetration of liberal democratic values in the clinic. This is evidenced by the broadly accepted practice of informed consent, the proliferation of consent forms, patients' advocates and ethics panels in hospitals and community health programs.

However, while I acknowledge that bioethics has become an integral part of medical decision-making, it does not change the fact that patients are politically weak when they fall ill and seek medical attention. And, this weakness is less the result of social policy than it is a consequence of the unique intersection of the physical, psychological, social, structural and economic vulnerability



of illness and, of the matrix of medical culture, knowledge and power. I claim that there is an intimate powerlessness of the sickness that cannot be alleviated or even properly mediated by the liberal norms of bioethics. As such, current notions of equality and autonomy do not effectively address the deep vulnerability of patients and, may indeed even be unintentionally destructive to patients' relationships with clinicians by fostering a false expectation of "equal" treatment.

Discourses about equality and rights fail to properly describe and facilitate relationships which are characterized by an imbalance of knowledge and power. Liberalism has been useful in establishing robust political and economic national communities and in regulating the individual's relationship to others in his/her society and to the state. However, feminist critics of liberalism quite rightly point out that the private realm—the realm of the family and, of intimate and trust-worthy relationships—is less amenable to conceptions of rights, equality and autonomy. Despite being equal citizens, everyday we are immersed in relations which are unequal—we are parents, children, doctors, patients, lawyers, teachers, students and, clients—and these interactions are, of necessity, built on imbalances of power and knowledge that cannot be erased. Slapping a template of egalitarianism on top of these hierarchical relations is ineffective. More importantly, it tends to mask ongoing structural inequalities. Speaking about equality and autonomy in these instances does not do justice to the complexity and interdependency of these types of associations. It seems instead that our notional equality allows us to decide when, where and with whom to place our trust when we need advice, assistance and/or care. Despite our political rhetoric, our autonomy is not absolute and our mortal stature requires that we experience dependency at various and ongoing moments in our lives. The clinical setting and on the interaction between doctors and patients provides a poignant example of the problem that this issue of trust poses: we trust our physicians to possess and act on a specialized knowledge but, even as they assume the power of their profession we hope that they do not use their power in a wanton, patriarchal or disrespect manner—in other words, we still want to feel as though we are equal even if we are, for all practical purposes, not.

### **Patients Internment in the Positivist Culture of the Clinic**

In reading memoirs of ailment from a variety of liberal democracies,<sup>1</sup> I observe two things: Firstly, these narratives provide an opportunity for spiritual reflection about physical and psychological suffering. Secondly, and more importantly for me as political, legal and feminist theorist, stories of illness describe the social and political conditions of being a patient. It is the deep vulnerability of illness that strikes me. Patients are weak not only as a result of physical and psychological affliction; they are weak because they lose a portion of their agency and equality when they enter the medical system. It becomes apparent that despite ethical and legal efforts to safeguard patients' equality through the institution of medical bills of rights and bioethics codes, patients feel bereft of political capacity.<sup>2</sup> Becoming ill necessitates a contemplation of human morbidity and mortality. Seeking the aid of a

physician and, in turn, becoming a patient results in a diminution of social and political status. Ill individuals certainly retain notional equality but, as they unclthe themselves literally and metaphorically in front of clinicians, they discover an intimate powerlessness pervades much of the interactions between doctors and patients.

Illness narratives leading up to the late twentieth century tend to focus on human ailment as a mortal threat and as an opportunity for spiritual reflection. The deep sense of suffering and isolation associated with ailment creates the possibility to reconceive an individual's place in the social and metaphysical cosmos. John Donne's popular poem: *Devotions on Emergent Occasions*, which he wrote in response to his own illness, is emblematic of this form. The poem details Donne's illness and recovery and, his consequent reflections about man and God. His meditations combine intimate emotions with larger moral observations. Sickness, for Donne, reminds man of his feeble mortality amidst God's immortal cosmos. To be ill is to be reminded of humanity's small, mortal stature. He urges us to trust in external forces: in the apothecary and (more importantly) in God.

In the 1920s, Katherine Mansfield, who is dying of tuberculosis, believes, like Donne, that her illness can transform her spiritually. She hints that her 'ill-health will allow her to repair' into something greater. She hopes for a metamorphosing revelation which will make life more livable. But, despite her spiritual aspirations, Mansfield finds her suffering unbearable. Alone, and in pain, she writes that she must perforce be her 'own doctor' in enduring her physical and mental anguish. Her illness is a fearsome and lonely prospect. Virginia Woolf also experiences isolation when she is confined to bed with a bout of influenza during the 1940s. Although her life is not threatened, Woolf nonetheless expresses a metaphysical moodiness. While her essay, "On Being Ill," lacks Mansfield's agony, it successfully captures the lonely melodrama of illness. For the stricken individual, the mundane aspects of life recede. Business affairs no longer seem important. Some friends appear toadish, while others become magnificently beautiful. Sickness alters memory and the perception of time. It dislocates the senses. All that is ordinary is transfigured. Restricted to one's quarters, the ill person looks to healthy existence as a passenger looks to a 'remote and fair' shore from the deck of a 'ship far out to sea.'

Donne, Mansfield, and Woolf all express a spiritual longing or awakening. In the midst of pain, they discover a mystical tie to God and/or the universe. Thus, in spite of its physical manifestations, illness evokes an invisible transfiguration of the soul. The suffering of the body creates an uncontrived opportunity for ontological contemplation. Illness provides the possibility that the ailing individual will discover a more meaningful understanding of what it is to be human.

While illness narratives of the late twentieth century certainly express the spiritual confoundment of earlier accounts, they also display a consciousness of the social meaning of physical dysfunction. They seem to express an awareness of the cultural and political significance of ailment. Virginia Woolf's account of the 1940s seems to hint at an emerging awareness of the social dislocation and isolation of sickness. Instead of experiencing a sense of metaphysical community, patients of the twentieth century begin to report a sense of social alienation in

their chronicles. The modern patient is conscious not only of physical infirmity but also of political weakness in a society which upholds the values of free, equal and independent individuals. Suddenly, the patient is no longer *quite* as equal as before. The impotence of disease is no longer merely physical but also political. The ill individual becomes subject not only to physical symptoms, but also to the social imagery and medical institutionalization of disease.

Susan Sontag's *Illness as Metaphor* and *AIDS and Its Metaphors* are cases in point. Originally published in 1979, Sontag's treatises explore the metaphorical hold that certain diseases have in the public imagination. The author sees sickness not only as an intimate physical and spiritual event but more notably as a situation which evokes complex social sentiment. Sontag's own experience of cancer thus becomes an occasion for intellectual observation and criticism of medico-social culture. The image of the ill person and its attendant metaphors are potent forces in any given culture. Susan Sontag categorizes them as punitive or sentimental abstractions. She attempts to decipher disease meaning and myth in Western society. Specifically, she examines tuberculosis, cancer, and AIDS. She compares and contrasts the personae of consumption and cancer, and explores cultural perceptions about AIDS. Her point is that the landscape of illness is fraught with metaphors that often contribute to, rather than alleviate illness suffering. Diseases become imbued with distinct disease personalities that tend to overwhelm victims. The patient's body, psyche and person are viewed to be latently "tubercular" or "cancerous." Consequently, the cultural weight of an ailment can eviscerate the personal significance of illness in an individual life.

In analyzing the metaphorical baggage surrounding sickness, Sontag proposes that allegories of ailment are dangerous on two counts: (i) they mediate an individual's encounter with illness and the medical system, thereby thieving the patient of a personal understanding of illness and, (ii) they make illness a primarily psychological event which blames the victim and can distract from valuable therapies. In sum, Sontag critiques the metaphorical psychologizing of disease. Discussions that focus on emotional origins place the onus of dysfunction on the patient, inducing an enormous amount of guilt. They also tend to remove the individual from the community of human sympathy.

Sontag writes out of a rage engendered by her own experience as a patient. Interestingly, she does not admit to being a former cancer patient until the writing of her companion volume, *AIDS and Its Metaphors*.<sup>3</sup> Her illness narratives are distinct. Written in a highly intellectual and distanced prose style, her books are an articulation of her resentment of the images and language associated with disease. She states clearly that common metaphors of illness discourse not only diminish experience through false stereotyping but also exacerbate both physical and psychological suffering. Moreover, Sontag views medicine as a highly practical discipline. Antibiotics, not hygiene nor economic prosperity, have lessened the incidence of tuberculosis. Radiotherapy, not psychotherapy, ameliorates cancer patients' conditions. In a sense, hers is a deeply conservative critique which does not acknowledge anything but the mechanical capacities of physicians. Medicine's attempts to provide ministrations to the psyche and the soul have no place in her understanding of clinical practice and disease modeling. For Sontag, physicians and case-historians often employ pre-

meditated fantasies to articulate facile epiphanies about illness. Obliquely put, transcendence is a deeply personal and even private matter. The struggle for her is to preserve the individual patient's identity and respect, as well as a subjective (and private) perception of meaning that prevails over enculturated stigma, disrepute and mawkishness about disease.

In her discussions, Susan Sontag explicitly attacks the writings of the physician, Oliver Sacks, for using "catastrophic neurological illness as the material for . . . portraits of suffering and self-transcendence, diminishment and exaltation." (Sontag; 125) For her, his writings typify formulaic epiphanies about human suffering. However, although Sontag objects to Oliver Sacks' collections of medical tales, he writes not only about patients but also about his *own* journey through illness. His volume, *A Leg to Stand On*, tells of a severe leg injury that results from a mountaineering accident. He rips his quadriceps muscle from his thigh after falling from an elevated ledge. After reconstructive surgery, his leg feels remarkably different; at times he can't even find it. The medical staff ignores and even denies his bizarre symptomology and Sacks is left in limbo. Terrified by his physical impotence and by his physician's oversight of the strange sensations emanating from his limb, he feels utterly alone. In the end, although Sacks is by profession a doctor, his story focuses less on physical suffering than on the alienating psychological culture of being a hospital patient.

He observes that the practical aspects of clinical care require that the sick person assume a posture of passivity. Others must act for the self when and where activity is no longer possible. The sick bed and sick room simultaneously protect and rule by enforced seclusion. Unable to master the chores of living and isolated from the populated, healthy world outside, Sacks must simply linger. Quite literally, he lies in wait for the healing attentions of both nature and the physician to take their course.

Sacks' desire to speak with his care givers about his condition dominates much of his thought while reclined in bed. He wants desperately to tell his story. However, he discovers that while he wants to engage in a dialogue about his treatment, the surgeons only wish to discuss the salient facts. The clinical conversation is peremptory and impersonal. Sacks feels thwarted and upset. To make matters worse, when, after surgery, he can no longer sense his leg, the attending physician denies that anything could possibly be wrong. The medical denial of his reality dislocates and unnerves him even further. "As a patient in hospital I felt both anguish and asphyxia—the anguish of being confronted with dissolution, and asphyxia because I could not be heard." (Sacks, *Leg.*; 209) Sacks' suffering arises out of an essential conflict in perception which occurs in medicine when the experience of the ill self clashes with the objectivity of the clinical gaze.

The divergence of perceptions and of narrative becomes most apparent in the interactions between doctors and patient. In one scene, surgeon and medical students enter Sacks' room without greeting him. Instead, they refer either to the chart on the end of his bed, or to the nursing Sister beside it, or to the leg bound in the cast. When Sacks stammers something about the unresponsiveness of his quadriceps, he is dismissed with a wave of the surgeon's hand. The

medical team soon sweeps out of the room. Later, when he is recuperating, Sacks glimpses at the chart which so often mediates the time he has with his physicians. He reads "Uneventful recovery." It is at this point he realizes the tremendous discord between his own chronicle and that of the staff. For him, recovery has been utterly remarkable.

Sacks' narrative sketches the particular, acute pain of the patient. He talks little of physical discomfort, but rather emphasizes the enormous psychological pain of hospitalization. Patients who feel passed over or muzzled, know the clinic's coercion. Medicine perceives, interprets and speaks in a manner which denies the perceptions, interpretations and language of subjective suffering. Sacks' narrative demonstrates that the clinic's dominance of the subjectivity of the ill self (in its need for apparently objective findings) is a coercive act whether or not it is overtly recognized as such or not.

The Canadian sociologist, Arthur Frank, writes of the distinction between illness and disease in his memoir, *At the Will of the Body*. Disease is an imposed medical category, whereas illness is a circumstance. Further, illness can be an opportunity for the discovery or recovery of life's meaning. Nonetheless, the clinic both insists on viewing patients in terms of disease categories rather than in terms of illness. Because the clinic demands the splitting of the self into a separate disease entity, its culture can become an obstacle to the reconstitution of the individual.

Like Sontag, Frank objects to the metaphors that colour discussions of disease and treatment. Medical staff and friends speak of his cancer in terms of a battle. Characterizing cancer as a battle turns the body into an external field upon which violent incursions are made. Treatment aims to colonize the body, to dominate it. As a result, the patient loses the capacity to be intimate with the illness experience. For Frank, unity remains paramount: trust in the sanctity of his whole being endows both strength and coherence to his agency as a human being. This singularity of focus (and not images of bombardment and dissolution) provides the necessary means for his repair.

Despite the best of intentions, Frank cannot, however, avoid the stigmatization that seems to be associated with his disease. He has difficulty enunciating the word cancer. He tries to mask the presence of an intravenous line in his chest through layers of loose clothing. Finally, the loss of his hair to chemotherapy labels him decisively as a patient—it marks him as someone who has been colonized by disease—and he dons a hat to cover this last sign. Somehow he cannot avoid turning himself into an object of stigma. While Frank does not discuss metaphors in any detail, he hypothesizes that cancer is so strongly mythologized in society that the sufferer cannot evade being cast within its allegory of evil.

To fall prey to stigma means that the individual transmutes into the disease itself. The disease overtakes the persona. In this sense, the patient becomes the locus of management rather than of the illness experience. A diagnostic grouping may be useful for treatment but it is not efficacious to *care*. This dichotomy reveals itself when Frank first goes to his doctor and discovers that tests, and not communication, form the basis of the medical exam. To his greater surprise, his physician does not even touch him. It is only when he

shops for a third opinion that his body is finally palpated. This physician feels a mass and, just by the way he looks at and speaks to him, Frank feels better even though he now faces the prospect of a tumour. However, when cancer is confirmed in the laboratory, the oncology specialist is an excellent technician but a lousy communicator. The new cancer patient calls it "a triumph of science and a lapse of humanity." (Frank, *Will.*; 27)

Poverty of communication is so pervasive that it seems to be a constant and malignant side-effect of the clinic itself. And like Sacks, Frank feels isolated and silenced. His voice is not important to those who treat him. Ironically, the hospital conducts psychosocial surveys of its patients, inquiring about problems and stress within the family or at home. Although the questions in themselves indicate a level of caring, the environment in which they are asked—behind a "privacy" curtain in a public ward—is hostile to any honest response. He and his spouse weigh their options and choose to remain silent, for they feel that if they expose their acute and deep vulnerabilities to the medical staff and do not receive total and unconditional support, their suffering will only have been aggrandized by the clinic's flimsy pretext of psycho-social counseling.

Frank's critique of the superficiality and inefficacy of psycho-social approaches in the clinic came back to me when I was recently admitted to an Emergency department; my partner and I were asked a new question about domestic violence and abuse. I also noticed a number of posters about domestic abuse in the bathroom and the corridor. When I asked about the new policy, the nurse admitted that while they were now required to ask the question, no one really knew what to do or say if a patient indicated that violence in the home was indeed a problem—no clinical training or discussion had taken place when implementing the new psycho-social intervention.

It is apparent that the spatial, temporal, professional and nosological organization of hospitals inhibits any valuable exchange between staff and patient.<sup>2,4</sup> Not only the lack of private space but the limitations of time place a terrible constraint on the relations between patient and hospital staff. A friend of mine who died of cancer in March 1996 writes of her first day of chemotherapy: "Sailing along beautifully (with the occasional tiny low point) ... But today appeared a certain W. B.—nurse clinician—who was supposed to talk to me about my prognosis. However she'd been away at a conference for 13 days and was trying to cover in one session what should have been done in four ... Very down. After session." (*Journal*, Rea Wilmshurst, 21 February 1995) Even when team members try to employ psychological approaches with patients, they often fall short because clinicians lack the appropriate, private environment; the requisite time and/or the proper training to provide emotional support. Furthermore, the theoretical models are rather so generalized that they function much like astrological categories or mass market self help books, they are vague enough to be broadly applied, but provide just enough detail for patients to believe their own lives are being illustrated. Through the psychologizing of disease the patient can thus feel responsible for the anti-social behaviour of sickness, thereby encouraging a pernicious belief that ill health is evidence of emotional weakness. Thus, even in the well-meaning psychological management of disease, constrained and inappropriate paradigms can replace true insights. Moreover, because clinicians rely on disease models, ill people



not only become embodiments of lab results and scanning images *but also of* psychological propensities which are associated with specific disease types.

A theme of powerlessness runs through Sontag's, Sacks', Frank's and others' stories of hospitalization. They speak of a sense of diminishment that is reminiscent of the inefficacy of childhood.<sup>3</sup> Encumbered by physical infirmity, patients suddenly discover that they are diminished socially and politically. They feel less relevant even though they are at the locus of medical activity. They experience a loss of personal agency which induces a carceral sense that they are prisoners of both social metaphor and of medical objectivity. Medical language and paradigms overtake the patient's voice and subjective sense of self. An absence of communication is thus a common motif in accounts of patienthood. Patients discover that ill health occasions a vulnerability, necessitating dependence on care from others. However, the relationships between doctor and patient are one-sided to the extent that they allow the sick person little effective voice in the administration of care. Themes of power and powerlessness interpenetrate illness narratives. The very nature of illness renders individuals weak and debilitated—needing assistance. Usually, the mere fact of an ailment jeopardizes one's stature within a family or community. This is a part of the human condition and is certainly not the consequence of medical intervention. However, medicine's engagement of disease in the patient often contributes to the erosion of the patient's sense of self and, of his/her sense of equal stature within the hospital and the broader society.<sup>4</sup>

## The History of Objectification in the Clinic

The French philosopher, Michel Foucault observed this loss of equality in the internment of patients and ascribed it to the peculiar and insidious intersection between biological, scientific knowledge and institutional power. He writes that in psychiatry and medicine " . . . the doctor is qualified, the doctor knows the diseases and the patients, he possesses a scientific knowledge . . . [which] authorizes him to intervene." (Foucault, 1994; 44) Clinical knowledge endows authority. And, clinical institutions support a professional expertise which is associated with the mastery of disease and diseased bodies. For Foucault, knowledge produces power and, power in turn produces its own objects of discourse and fact. It is a symbiotic relationship. Thus, medical language and space are both constructed by and create a nosological reality in which the physician knows and does what the patient cannot.

In his work, *The Birth of The Clinic*, Foucault explicitly chronicles the rise of scientific, medical institutions in 18th century France (Foucault, 1973). Here, he describes the lifting of the prohibitions against *post mortems* in post-revolutionary France as the main impetus for the positivist transformation in the manner in which clinicians view illness and disease. No longer confined to the arbitrary complaints and symptomologies of patients, doctors can see the fruition of disease in the corpse. For the clinician, the consumptive cough no longer signifies the subjective suffering of the ill individual but rather the necrotic lung tissue of the cadaver. The locus of medical attention falls away from personal accounts of sickness and turns to the dead body as the arbiter of truth. An autopsy provides a tangible portrait of the course of disease in

the living. As a result, Foucault argues, a form of discourse develops which collapses speech (*parole*) and observation (*surveillance*) into one action: the gaze (*regard*). A simultaneity of language and perception occurs in which the doctor gives voice immediately to what he observes B the word and the observation happen in the same moment. It is a moment of objectification. This potent alliance produces a clinical culture in which facts dominate personal experience and the subjectivity of illness begins to recede.

This new positivist view of illness requires a space within which to develop and practice. Hospitals thus serve as locales in which diseased bodies can be isolated from the social pollution of the outside world. Foucault argues that clinics become isolated and distinct spheres and doctors become the manufacturers of truth within these spheres. The emergence of hospitals allows physicians to more clearly observe the facts of disease as they manifest themselves on the body of the sufferer. In this sense, the disease and the patient become a form of spectacle. Moreover, the indigence of most 18th century patients adds to physicians capacity to isolate, objectify and dominate them in pursuit of medical fact. It is socially unacceptable for these lower class and largely female patients to defy authority.

Although Foucault proposes that clinical positivism first arises in the late 1700s, medical capacities are in fact severely limited for almost another century. The clinic's penetrating glance is finally rewarded by the rise of bacteriology in the late 19th century. Between 1870-1900, bacteriologists make a number of discoveries which leads to the creation of the germ theory of disease. Two schools of study emerge: one in France under Louis Pasteur and the other, in Germany, under Robert Koch. Both groups of scientists undertake remarkable experiments during this period with a variety of bacteria. They achieve stunning results. Pasteur develops the anthrax vaccine in 1881 and rabies vaccine in 1885. Koch's experiments result in the discovery of the tuberculosis bacillus in 1882 and the cholera bacillus in 1883. Klebs and Loeffler identify diphtheria in 1883 and 1884. The postulate that germs are largely responsible for disease revolutionizes medicine. With the aid of bacteriological science, doctors are no longer satisfied with the dissecting gaze of their predecessors, physicians stimulate the body with vaccines and inoculations. The body's immune response to injections of attenuated bacteria, in turn, vanquish microbes. Illnesses that had formerly ravaged populations can now be identified and conquered by physicians. Consequently, medicine achieves greater potency, greater positivism and greater prestige.

By the early 1900s, the wide acceptance of germ theory signals the convergence of science and medicine. Medical positivism finds fertile soil in scientific thought. To be successful, a doctor has to perform two roles: that of the practitioner and that of the scientist. The enormous achievements of the bacteriologists turn the medical laboratory into a sacred space. The reduction of sickness to a stain of bacillus takes on an evangelical quality. The locus of study is removed from the body itself and moved to a more perfect realm: the laboratory. Medical facts emerge in the absence of the incarnate patient. Physician observation and discourse takes place (for the most part) separate and apart from the ailing body. It is at this juncture that medical discourse moves further from the sullied dependency on symptomology and subjectivity and into

the righteous reliance on quantifiable *fact*. Today, at the inauguration of the twenty-first century, an array of subsidiary professions has arisen to meet medicine's increased technology. Hospitals now employ a variety of experts who handle the tools and machines of observation. They also create and interpret much of the data for physicians to review during the diagnostic and treatment process. In addition, the allied health professionals (e.g., physiotherapists, occupational therapists, nutritionists, technicians, psychologists, etc.) have emerged as aides to doctors' expertise. They provide adjunct services which come out of medicine's increased understanding of human pathology's interaction with day-to-day function. The contemporary patient is thus submerged in a complex matrix of relationships with all of these experts in an effort to regain health. This diversification of contact means that the individual patient experiences an attenuated relationship with his/her physician, in which the doctor retains primary authority but other professionals perform bodily tasks which are more intimate to the body.

As a consequence of the expansion of personnel in the modern hospital, strong hierarchies of knowledge exist in the clinic. Health care practitioners are heavily stratified. Specialists and staff physicians are at the top, with residents, interns and medical students layered beneath them.<sup>5</sup> Therapists and nursing staff remain an echelon below that of physicians. They have neither the professional, scientific expertise nor the power to challenge medical authority. To some extent, these "lower" professions carry out a doctor's orders and their actions are an indirect manifestation of his/her will. The feminist theorist, Joan Tronto, argues that care is gendered, raced and classed. Those in traditionally male roles (i.e., doctors) either "care about" or "take care of" others. This means that they take on the responsibility for planning activities of care without actually participating in the hands-on work of care provision. "Care-giving involves physical work and requires that care-givers come in contact with the objects of care." This labour traditionally falls to women, lower class women and people of colour (Tronto, 1993, 101-124). Finally and inevitably, patients exist at the lowest end of the spectrum. They not only lack the privileged knowledge of the health care experts who care for them but they also lack a familiarity with the discourse and linguistic expressions of the clinic. Even though they express the symptoms of sickness, they are removed and isolated from the manifestation and construction of the disease they embody.<sup>6</sup>

### **The Idiosyncratic Layout and Language of the Medical Narrative<sup>7</sup>**

The increased use of laboratory sciences as well as technology means that medicine is even further removed from the body. While physicians still examine patients, they likely trust tests and/or scans to provide the most meaningful information. Temperatures, blood pressures, and, respiratory and heart rates are constantly monitored. Blood is tested, not just once, but often on an hourly or daily basis. Innumerable parts of the body can either be biopsied or analyzed at the cellular level (e.g., muscle tissue, bone, organs, blood, urine, semen, cerebro-spinal fluid, etc.). Diagnoses are made on the basis of lab results, electrical studies and, radiological and magnetic imaging. These tests confirm certain symptoms and allow B from the perspective of the patient B the

physician to put aside those subjective complaints which can seem extraneous to the making of a diagnosis. In this context, medical charts notate fewer and fewer symptoms and more and more clinical *data*. Patients charts are collections of tables, graphs and notations which are designed in a format which provides quick and accessible access to the "facts of a case."

Understandably, a distinct system of record-keeping must be adopted to keep details in order. One medical textbook states: "Because of the medical record's complexity . . . [It is] a road map of potential patient care problems. The record should be well organized, easy to read, and accessible to all." (*Mastering Documentation*; 3) A hospital generates an enormous number of reports during any one stay. Various types of chart-keeping methods proliferate modern health care. The most common are POMR (Problem-Oriented Medical Records), PIE (Problem, Intervention, Evaluation), Focus and CBE (Charting By Exception). The majority of approaches organize information around identified problems and not necessarily by symptom. Most of them incorporate the SOAP(IE)R technique which stands for Subjective, Objective, Assessment and Plan (Intervention, Evaluation, Rehabilitation). Subjective is the section reserved for transcribing the statements and complaints that a patient makes regarding an identified problem. Objective encompasses the apparently dispassionate observations of the health care worker. It is the current manifestation of Foucault's eighteenth century gaze. It is the naming of things in a clinical and disinterested manner. Assessment is intended to be the evaluative area of the record, providing a summary of the situation and a conclusion. Plan outlines the treatment plan or intervention. This method can thus identify and record any number of problems on any given patient. New advances in charting propose an "integrated" method in which each health care professional comments simultaneously on each of the problems identified by SOAP(IE)R. Finally, in addition to hourly handwritten notes in SOAP(IE)R format, a medical record contains a variety of other papers, such as a medication administration records, graphs, laboratory, pathology and imaging results, consultation notes from other specialists and, discharge planning notes (among many others). Hospitals increasingly use computerized databases to track all of this information.<sup>8</sup> The medical narrative, for the most part, is barely chronological, rather its structure consists of a gathering of objective findings into a visual format. This format is arranged so that apparent trends in the data can be easily reviewed, analysed and discussed.

The chart embodies a system in which facts and data can be efficiently categorized and pigeon-holed. As such, the medical chart compresses time into statistical and static graphs. Clinicians view patients' bodily functions (i.e., temperatures, fluid intakes and outputs, blood pressures, blood tests, respiration rates, etc.) as two dimensional maps which reconstruct the temporal arrangement of symptoms and signs of illness. This remaking of the body is its representation. Marc Berg and Geoffrey Bowker state: "At this point, it becomes meaningless to debate whether these interventions address the body "itself" or its representation, since it is *in and through* this representation that the body itself is known, surveyed and intervened upon." (Berg and Bowker, 1997; 518)

A Weberian type of re-ordering of the patient's body takes place in which the possessor of medical knowledge creates and sustains a matrix of classifications which only other medicos understand and have access to. A community of practice forms around this activity of cataloging in which only

members understand the terms of reference. Necessarily, categorization requires comparisons with normative paradigms. The reduction of illness to disease and, in turn, to fact requires judgment. This judgment determines what is important or real in medical terms from what is unimportant or nonexistent. "The [medical] glance is silent, like a finger pointing, denouncing." (Foucault, *Birth.*; 121) The denunciation is without rancour but is nonetheless hostile to the contextuality of the world outside and prior to disease. Geoffrey Bowker and Susan Leigh Star write about the consequences of this type of classification. They describe the process by which objects become 'naturalized'—i.e., the manner in which specialized members of a given community no longer recognize the contingent nature of the categories they work with and articulate. (Bowker and Star; 1999) They write: "We need to recognize that all information systems are necessarily suffused with ethical and political values, modulated by local administrative procedures. These systems are active creators of categories in the world as well as simulators of existing categories." (Bowker and Star, 1999; 64)

The medical chart thus develops and supports a language unto itself. Not surprisingly, the record exhibits a particular vocabulary that remains quite distinct from that of the general population. Its recorded perceptions are largely inaccessible to lay people and are both consciously and unconsciously shrouded in secrecy. Latinate words and acronyms appear throughout (as they have done for the past two or three hundred years). Scientific and technologic terms appear as well. Consequently, the language of the clinic diverges from that of the general populace. The privileged learning of the clinic not only dominates through the power of its gaze and the strength of its positivist culture but also through a language which is largely incoherent to non-medical persons.

Although Latin is a 'dead' language, it remains a vital part of much professional vocabulary. Law, medicine, the academy and the church all employ Latinate phrases. Historically, it is a language which has been associated with knowledge and power. For centuries ordinary people could not read books or understand religious services because they were composed and spoken in Latin.<sup>9</sup> Only those with the appropriate learning and social standing could comprehend the law, anatomy and written texts. The continued use of Latin in medicine is thus a remnant of a period in which social hierarchy was paramount and when the withholding of knowledge from common folk was an acceptable practice. The continued use of Latinate short forms, words and phrases in the clinic form an effective barrier between physicians and patients. It encourages a privileged type of discourse.

And even when clinicians use English, ordinary words can become transformed within the medical setting. Scientific and technical language can obscure the everyday meaning of what is being discussed and recorded in patient's chart. Moreover, short forms abound in the clinic. For example, *b.i.d.*, *t.i.d.* and *q.i.d.* are acronyms for two, three and four times daily. *P.O.* and *N.P.O.* stand for 'by mouth' (*par os*) and 'nothing by mouth' (*non par os*) respectively. Understandably, these initials are largely incomprehensible due the fact that they are derived from Latin. Nonetheless, English short forms exist which remain unintelligible to the lay person. For example, *R/O* means 'rule out;' *SOBOE* translates as 'shortness of breath on exertion;' and, *CHF* replaces 'congestive heart failure.' These are examples of some of the innumerable

ways of expressing medical terminologies in shorthand. These methods save time for the professionals who both record and read notes. However, in creating a narrative which is abbreviated in both form and content, physicians fashion a chronicle which is endowed with an altered significance from the patient's perspective.

For example, to indicate that a question has been asked and responded to in the negative, doctors employ the word "denied." (Doctor: "Do you have pain?" Patient: "No."—This interaction is noted in the chart as: *Patient denies pain.*) Outside the clinic, "denied" implies a host of things. The phrase "Patient denies pain" could be interpreted as the patient *will not admit* to pain, and is thus suspicious or untrustworthy. Or perhaps it could be seen as the patient is *in denial*, and thus cannot know or articulate him or herself accurately.<sup>10</sup> Other terms such as "insufficiency" and "failure" also occur regularly. These usually are meant to mean less than normal or a cessation of function. Nonetheless, they could imply a lack of character or will, if not on the part of the patient, on that of the body.

Further, violent metaphors abound. Sometimes it is not clear whether the doctor conducts an all out attack on the disease or the patient. For example, in discussing cancer therapies, Susan Sontag writes:

Treatment...has a military flavor. Radiotherapy uses the metaphors of aerial warfare; patients are "bombarded" with toxic rays. And chemotherapy is chemical warfare, using poisons. Treatment aims to "kill" cancer cells (without, it is hoped, killing the patient). (Sontag; p. 65)

Moreover, the brutal language of the gaze can also unwittingly portray the patient as unreliable, unable and guilty.<sup>11</sup> To return to Foucault, medical language has an aura of righteousness. As a result, the patient can seem to fall under suspicion, or even outright hostility.<sup>12</sup> This happens when the idiosyncratic language of the text manages to colonize the patient's experiences through its objectifying, alienating and sometimes violating terminology. The dispassion and militarism of the medical effort to fight disease progresses until it is metaphorically transferred onto the ill individual. The patient becomes the disease who is also the identified enemy. It is at this point that medicine oversteps its valid purpose and commits a moral-political harm. The medical record represents the political arrangement of knowledge and behaviour in the clinic; it is thus a political document. It plays a central role in the creation of the *body politic* in which the record unearths and displays the secret pathologies which the ill body conceals.

Moreover, the medical chart not only configures the abstracted body of the patient but it also mediates clinical relations between varieties of clinical personnel. (Berg and Bowker, 1996) Significantly, the emphasis on communication in the clinic is not between patient and practitioner, but between health care professionals. All those who come in contact with a patient must document the interaction. Medical language serves the larger community of health care. In this sense, the medical record serves as the institutional memory of a patient's journey through medical care. But while the chart is often a primary means of communication between staff, the physician retains



primary authority over the record, and thus over the patient. S/he possesses the unique ability to write *orders*. Orders consist of physician directives. They have absolute power as well as legal sanction. They preside over other health care personnel and patients alike. Through the creation and authority of the chart, physicians come to manifest the action and culture of the clinic as a whole. Accordingly, the record reflects and reinforces the disciplinary hierarchies within the hospital. (Nursing notes, for example, are usually the first portion of the chart which is destroyed or removed when a patient's chart is stored.) The production, collection and distribution of the information within the medical chart simultaneously embody doctors' professional prerogative as well as the objectified and abstracted vision of the patient's diseased body.

In the present age, Foucault's positivism has been carried out to a full purpose. From the advent of the *post mortem* through the rise of bacteriology and the consequent need for statistical record keeping to the increased use of technological and clinical data, medical discourse and knowledge has moved further and further away from the realm of the subjective account of the patient in *anamnesis*.<sup>13</sup> The patient's chronicle of illness has been overtaken by objectified facts and discussions of disease. By becoming objects of the medical gaze, patients enter a realm in which their agency and equality cease to be apparent. And while physicians are not necessarily conscious of inhibiting patients' autonomies, clinicians belong to a sphere of knowledge, architecture and action which often seems grossly antithetical to the realization of anything more than notional equality.

### **Creating Notional Equality—the Case of Bioethics**

In the last 30 years, biomedical ethics has assumed a large role in the attempt to construct more just interactions in medicine. Armed with philosophical concepts such as equality, rights, autonomy and utilitarianism (among many others), bioethicists have tried to address the problem of paternalism in the clinic. They have sought to provide frameworks with which to assess and discuss moral disagreements within medical science. As a relatively new field, it draws upon the interdisciplinary expertise of theologians, philosophers, lawyers and physicians. Its mandate covers a multiplicity of issues from creating guidelines for genetic and reproductive research to authoring dictums which govern truth-telling, consent and confidentiality in the physician-patient relationship. For many, bioethics has effectively addressed, and continues to address, the ongoing moral quandaries that are embedded in the health care setting. But while clinical ethics has certainly created a fissure in the edifice of medical practice by reminding both physicians and patients alike of moral obligations and rights, I believe that it is not able to speak to the structural constraints which contribute to inequities within the clinic.

A perusal of most bioethics texts reveals a two-pronged approach. Firstly, abstract theories of "deontology" and "utilitarianism" are laid out. Authors establish concepts such as right, autonomy, act-utilitarianism, rule-utilitarianism, paternalism and beneficence as tools in the dissection of moral problems. Secondly, case-studies appear to illustrate the depth and variety of ethical conflicts in the clinic. They contextualize the moral dilemmas

which clinicians face in the field. Concerns about human experimentation, epidemiology, suicide, abortion, euthanasia and resource allocation arise out of the stories which are laid out as the facts of a case. The bioethicists then sift through the various competing claims and determine which theory or value is the most applicable to each situation. While I do not dispute that bioethics has made a significant contribution as a formal bridle on medical habits, I am not convinced that it is truly effective in mediating the intimate interaction between doctor and patient and/or the structural hierarchies of the clinic. Firstly, it tends to apply templates of egalitarian and liberal thought to a relationship that remains unequal in terms of knowledge and power. Illness narratives indicate that formal equality does not actually assist individuals in mitigating the powerlessness of patienthood. Secondly, bioethics' precepts are ones which seem to be externally imposed without much regard to the contextual environment of the hospital or doctor's office or the patient's experience. Health care settings are often economically, physically and temporally hostile to the values espoused by ethical codes. Physicians are often too busy and receive little or no financial compensation for the time they take conversing with patients. Hospital rooms seldom offer more than anything but an illusion of privacy with the pulling of a translucent curtain. Patient information may well be confidential but it is essentially open to any health personnel who have access to the ward desk. And conversations about patients take place in corridors and elevators as medical teams move between rooms and floors.

Finally, bioethical principles do not seem to actively address the interdependence which exists between doctor and patient. They seem instead to act as prohibitions rather than facilitators in medical relationships. Patient consent forms are seen as legal hurdles in the pursuit of treatment. While procedures do not take place without the appropriate signature on the appropriate form, the signature itself does not signify the extent to which the patient actually understands the treatment or the context of an individual's consent.<sup>14</sup> The principle of consent has thus come to symbolize the patient's assent to medical activity but not the substance of that consent or the nature in which it was obtained. In this way, bioethical safeguards do they seem to recognize the imbalance of power which persists and remains a part of liaison between patients and physicians. Discussions of traditional liberal autonomy do not grasp the complex politic of the doctor-patient interaction.

This fundamental problem is evidenced by the fact that practitioners and patients continue to have difficulties despite the well-intentioned efforts of ethicists. This trend is well-documented in the results of the SUPPORT—Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment—project (SUPPORT Principle Investigators, 1995). This multi-million dollar investigation identified problems and tried to improve the relationships between physicians and profoundly ill, hospitalized patients.<sup>15</sup> Unfortunately, its efforts failed to ameliorate the dynamic between doctors and patients. The study enrolled 9,000 individuals and had two phases which took place over a period of four years. The first two-year phase managed to "isolat[e] several disturbing features of hospitalized dying and put together an intervention expressly designed to resolve them." (Moskowitz and Nelson, 1995, S3) The second two-year phase attempted, through a variety of tactics, to facilitate the communication between severely ill patients and physicians. Unfortunately, once the results of the study

were tabulated, it was revealed that these interventions had no impact on "patients' reported preferences regarding either resuscitation or the levels of communication with physicians." (Moskowitz and Nelson, 1995, S3) Only 15 % of physicians spoke to patients about the information contained in the reports. Of those patients who had not discussed resuscitation with their physicians, 41% indicated a desire to do so (Marchall, 1995, S9). Moreover, "only half of the doctors allegedly given information about patient preferences acknowledged that they had seen such information." (Berwick, 1995, S21) Despite the project's interventions, the patient-physician interactions remained unchanged.<sup>16</sup>

A number of theories exist as to why SUPPORT failed. Some of these stress that previous attempts to strengthen patient autonomy in the clinic through advanced directives and consumer choice models have also failed (Davis, 1991; Lo, 1986; Schneiderman, 1991). Patients want physicians to take the lead in decision-making, as the illness experience can create confusion about choices (Schneider, 1995, S27). Additionally, both patients and physicians tend to be overly optimistic about prognoses and treatment outcomes. Moreover, various patients and practitioners may assess similar situations differently (i.e., a patient or physician may view a situation more optimistically or pessimistically than another patient or physician). In this context, the failure of this study (and others like it) lies in its excessive presumption that rationality prevails in situations of morbidity and mortality. One conclusion might be that the illness context is one which is resistant to rational choice modeling and thus to moral (i.e., liberal) theories which presume a preeminence of reason.<sup>17</sup>

Another critique of SUPPORT focuses on clinical culture. As one commentator states: "The SUPPORT intervention's inability to produce any modification in patient care illustrates profoundly the force and tenacity of Western biomedical culture." (Marshall, 1995, S9) The bioethicist, Daniel Callahan, claims this culture is aggressively treatment oriented, deaf to patient's wishes, unwilling to take prognostic information seriously and, deeply ambivalent about the place of death in human life (Callahan, 1995, S34-35) Even though the participating physicians and patients were interested in changing their communicative patterns, ". . . when involved with their own situation . . . they felt they were doing the best they could, were satisfied they were doing well, and did not wish to directly confront problems or face choices." (SUPPORT Principle Investigators, 1995, 1596) Given the socio-political culture of hospitals, the study's methodology is suspect because it relied on nurses to act as facilitators and this merely replicated the hierarchy of patient care in which nurses talk to patients while relaying messages to physicians who are 'in charge.' (Marshall, 1995, S9) The project thus reflected the structures of social dominance in the clinic in which doctors do not listen to either nurses or patients because they are subservient members of the hospital hierarchy. "It is unrealistic to expect that a party with little voice [i.e., nurses] in the system [would] have a major impact on it." (Emmanuel, 1995, S15)

## **Conclusion: Rethinking Rights and Equality in the Context of Clinical Culture**

In the end, an examination of patients' stories; of charting methods and language and; of the critiques of SUPPORT, all disclose that there are formidable, structural barriers in the clinic which prevent better communication between doctors and patients and discourage patient autonomy. Furthermore, the presence of ethical codes as well as bioethicist's concerted attempts to have physicians pay attention to these codes succumb to the structural and cultural pressures of the clinic. Practitioner and patient behaviour remains static. The presence of medical ethics does not seem to alter the exchange between doctors and patients.<sup>18</sup> As the representative of liberal rights in the clinical environment, bioethics does not seem to have been able to reconstruct the clinic so that it can support the agencies of ill individuals. In some sense, the results of the SUPPORT project shows us that the discipline's edicts remain largely outside the parameters of medical activity. Rights have not been able truly to penetrate the clinic. Moreover, it is unclear whether rights are in fact the best way to describe and facilitate doctor-patient liaisons. The SUPPORT project raises political questions as to whether medical hierarchies and culture (as they exist now) can accommodate liberal values and, whether liberal values themselves are the best means for facilitating change in the clinical environment and in professional care relationships.

To this end, feminist discussions of autonomy often highlight the problem that liberal rights do not mediate relationships very well. Traditional liberalism focuses on the individual rather than on the construction and maintenance of just interactions between people. In a number of articles, the feminist legal theorist, Jennifer Nedelsky, proposes that autonomy should be reconceived as relationship. She comments about traditional liberal theory: "The values we cherish have come to us embedded in a theory that denies the reality we know: the centrality of relationships in constituting the self." (Nedelsky, 1990, 9) She advocates a more contextual and less atomized notion of selfhood and autonomy that would allow people to be self-determining within relationship to one another. And, in my opinion, it is this type of reconstruction of autonomy which medical ethicists would be wise to acknowledge.

One feminist critic who has begun to make inroads into biomedical ethics is Susan Sherwin, a feminist philosopher. She calls for change in the focus of medico-moral discussions. In her book, *No Longer Patient*, she emphasizes a more realistic approach to deliberations in which both patients and doctors are viewed as participants in larger social relationships. Sherwin's point is that ethicists need to recognize the social construction of the autonomous self. Moral problems and the pursuit of individual agency take place within highly complex political matrices of race, class and gender. She writes: "What feminist ethics claim is that oppression is a pervasive and insidious moral wrong and that moral evaluation of practices must be sensitive to questions of oppression, no matter what other moral considerations are also of interest." (Sherwin, 1992, 57)

The limits of traditional ethical interventions in medical practice are evidenced by patients' persistent sense of vulnerability when seeking medical

care. While established ethical edicts seek to safeguard individuals' liberties from the paternalism of the clinic, they do not always work in the manner in which they were originally conceived. For example, the principle of informed consent seems to be unassailable from a theoretical standpoint. However, the process for obtaining consent from patients can often be treated as an obstacle in rather than a facilitator of the professional relationship. The proliferation of generic "consent" forms is an indication of the extent to which authorizing consent has become a legal, ethical formality in medical practice. It is seen as a hurdle to be surpassed rather than as a substantiation of the individual's trust in a particular physician or procedure. In this sense, the patient's so-called right to be informed of the risks of medical treatment and his/her capacity to accede to any given treatment protocol meets conventional liberal requirements for respecting individual autonomy but it does not really address the substance and quality of that individual's autonomy. Moreover, it is not clear, to what extent that individual is in fact exercising true personal agency given the ongoing imbalance of authority in medical relationships. What exacerbates this problem even more is that these relationships are conventionally seen as belonging to the private sphere and are thereby usually protected from rigorous moral scrutiny by the broader political community.

There are some medical reformers who propose that egalitarianism is still an obtainable goal in the doctor-patient interaction. These clinicians focus on creating "patient-centred" practice. The aim is to revise the authoritative encounter between doctors and patients. In this new approach both patient and practitioner share responsibility for goal setting and attainment. The physician's role is to help the patient help his/herself (Toops, 1998, 1992). The medical relationship becomes partnership. Some even suggest that doctors and patients will eventually sign contracts ensuring parity between the two participants. This will apparently allow an enhanced ability to pick and choose between physicians and to secure guarantees of certain types of care in advance of treatment. If any of the portions of the contract are not filled, both parties have immediate recourse. All of this is a type of legal restructuring of the relationship in an effort to reduce the physician's hegemony.

Unfortunately, the inequality of the relationship in the doctor-patient liaison is quite elaborate. And while some aspects of the medical hierarchy are ripe for reform, there are also legitimate bases for physicians exercising more power than patients: they possess a specialized form of knowledge which remains largely inaccessible to lay persons. Their authority is accompanied by a professional skill. And in the end, no matter what type of ethical revisions are made to interactions with patients, physicians still retain the proprietary right to prescribe treatment. If doctors were truly our equals in terms of accessing medical knowledge and facilities, we wouldn't need them. We would be able to minister to ourselves. The notion of a contractual interaction then does not do justice to the specialized knowledge of clinicians, nor to the particular vulnerabilities of ailing persons. The concept of contractual equality seems merely to mask the inequities of the relationship rather than exposing the subtleties of the interpenetration of knowledge and power.

By looking at memoirs of illness, it would seem that while bioethics has successfully provided legal and ethical guidelines for medical practice, it has

not addressed the structural constraints which continue to oppress patients in the clinic. It is all very well that physicians know that they *should* behave in certain ways; it is quite another thing to support those behaviours within a nosological, cultural and architectural environment which is hostile to true equality. The medical model tends to support rather than diminish patterns of oppression within our communities. Medical ethicists alone cannot really effect the necessary political changes that are required to reduce the sense of impotence and coercion that can accompany medical care. I suspect that the principles of bioethics are far too abstracted and ethics programs have been integrated far too effectively into medical institutions to provide the external criticism and substantial reconstruction of doctor-patient interactions. The lesson here then, is that in the end, theorists who do do work in both conceptual and applied environments need to take into account the political and cultural contexts of differing localities in order to be more successful in modifying human behaviours and practices.

I believe that relying on a more contextual understanding of autonomy, rights and equality and of the unique social construction of medical environments (i.e., the culture of medicine) can only facilitate the pursuit of justice in medicine. It will provide a keener ability to grapple with the imbalances of power which continue to persist between physicians and patients despite the fact that these relationships exist in a political and legal environment of notional equality.

Given the cultural and structural aspects of the clinic which inhibit equality, it becomes difficult to imagine fostering egalitarianism within medicine. However, I want to resist the Foucauldian notion that knowledge and power form an impenetrable alliance which create truths and a reality in which we in fact play an intrinsic part and, against which we have no defense. As I contemplate the problem of trying to reconstruct theories of autonomy I am acutely aware that we need a more detailed and subtle understanding of what it means to live in a formal egalitarian society. Despite the legal entrenchment of rights and equality, it seems that we partake in unequal relationships on a regular basis—and this is particularly true when we become patients and seek the expertise of physicians.<sup>19</sup> The rights and equality we possess in our public lives as citizens may not be appropriate templates to achieve relations of moral worth and trust in the private, care-giving spheres of our lives.

When people ail, the liberal paradigm of autonomously independent individuals does not easily fit the reality of weakened, dependent persons who need the tending of a physician to regain their independent status. It seems that trust is a central component in creating a just relationship. Contracts, *per se*, between independent equals seem inappropriate. Trust becomes a necessary ally of both physician and patient in negotiating their interaction. But determining the conditions of a trust which fosters justice is difficult to delineate theoretically. Medical ethicists have not successfully determined the nature of a trust between unequal parties which is neither paternalistic nor invokes a formal carcass of rights and equality. The central question that illness stories provoke is one which asks liberal, feminist and postmodern theorists about the optimal conditions of trust between individuals of varying knowledge and power, in a society which values equal moral respect. Given that neither paternalism nor rights has satisfactorily navigated the terrain



of patient-doctor relationships, how should we rethink the moral parameters of unequal, care-giving interactions while still promoting justice and autonomy for both parties? After all, justice happens between people; it is not an atomistic and isolated event.

What illness narratives teach us about medicine and, about ourselves, is that we need a moral frame that sees individuals as embedded in complex and unequal relationships and this new construction of justice needs to focus on the intimate exchange between individuals in order to foster a society of true equal respect. A moral tension exists between autonomy and dependence, equality and inequality which liberal rhetoric cannot resolve and thus which undercuts the effectiveness of bioethics in medical culture. This tension, as expressed by the divergence of patient narratives and medical records, demands that as theorists and critics we need search for better ways to describe our moral selves.

E&M

## Endnotes

- 1 Over the last several years I have done a detailed study of illness narratives which is part of a larger book manuscript being revised for publication. While I do not have the space to elaborate on these narratives, they form the basis of explorations in the opening sections of this paper.
- 2 I believe that the creation of these narratives attempts to transcend and remedy the powerlessness of patienthood. It is a performative act of personal agency. The socio-linguist, Nancy Ainsworth-Vaughn, argues that patients' stories serve two purposes: (i) they reduce the social space between physicians and patients and (ii) they assert a self which is repressed in institutional settings (Ainsworth, 1998, 148-150)
- 3 The theme of the re-emergence of childlike helplessness appears in other narratives. Author and stroke patient, Robert McCrum, writes in his diary: "It occurs to me that as a patient I am regressing to a state of childhood in some ways, surrounded by parents, waited on hand and foot. I feel like a child, and helpless like a child." (McCrum; p.75)
- 4 A number of authors, academics and physicians have explored the role that illness narratives play in constructing meaning for patients. Anatole Broyard, Arthur Kleinman and Robert Coles all delve into the complex world of patienthood. Their work has led to a call for physicians to pay greater attention to patients' stories when treating disease. This has led to the creation of a number of programs and departments which focus on 'the humanities and medicine' at a number of medical schools and health facilities. This interest in illness narratives has also fostered a subspecialty within the discipline of biomedical ethics.
- 5 Much has been written about the problems of hierarchy in medical education and so I do not spend much time on it here. However, the system of medical education which has arisen to disseminate clinical expertise indoctrinates students into the nosological and political mores of the clinic. While many medical schools have attempted to reform their methods for teaching undergraduate physicians by relaxing scientific requirements for entry, supporting joint ventures with the humanities and social sciences and creating smaller more intimate classrooms, post-graduate education remains deeply imbued with a hierarchical culture. Because post graduate education occurs on the wards, interns and residents play a fundamental role in the meting out of labour and authority. Part of internship is handling the scut work, or all the tasks that residents find tiresome and unappealing. Residents, in turn, also perform the duties which staff physicians find onerous. To this end, even as young doctors learn from their superiors, they are burdened with numerous and lengthy responsibilities. They are required to serve very long hours in the hospital (often for days and nights at a time) with little opportunity for rest or recovery until the next call schedule. Sleep-deprived, and often harassed by supervisors to research and present cases (i.e., patients), young physicians are indoctrinated into a relentless system of trying to demonstrate enough knowledge in order to move up the chain of power. Please see: Abrahamson S. Time to return medical schools to their primary purpose: *Education. Acad. Med.* 1996;71:343-347; Borek D. Unchanging dilemmas in American medical education. *Acad. Med.* 1989;64:241-244; Konner, M. *Becoming a Doctor: A Journey of Initiation in Medical School.* Penguin Books, 1987.
- 6 From a feminist perspective, patients are the most feminine members of the clinic, occupying the lowest and most apparently passive echelon. Moreover, patients are stratified themselves by gender, class, sexuality and race; with medical expertise and research habitually and historically focused

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- on the ailments of white, heterosexual, able-bodied, middle-class males. (This, despite the fact that women comprise the majority of the patient population.) As a result the subjective responses of those who belong to disadvantaged groups tend to be over-looked, devalued or even psychiatrized.
- 7 My familiarity with the language of chart-keeping comes not only from reading my own medical records but also from the chart review which I conducted during my master's research on resource allocation in a large urban cardiac unit.
  - 8 The communitarian, Amitai Etzioni, discusses the threat that current systems of computerized charts present to both patient consent and privacy. He proposes a number of institutional changes which would inhibit legal and illegal breaches of patient privacy and, tighten legal and ethical notions of patient "consent." Please see: Amitai Etzioni, "Medical Records: Enhancing Privacy, Preserving the Common Good." *Hastings Center Report* (Mar/Apr 1999).
  - 9 For example, a defining moment of the Roman Catholic church in the twentieth century was its decision to begin to conduct mass in secular languages rather than in Latin.
  - 10 Of course, "being in denial" comes from psychology and psychiatry, medicalized professions themselves.
  - 11 I believe that a whole paper could be devoted to the unconscious metaphor and sometimes quite deliberate descriptions of charting language. The inherent violence of medical narrative becomes apparent during even the briefest perusal of medical records.
  - 12 Please see Appendix A in which I show examples of a consultation sheet in which notable, but not exceptional language appears.
  - 13 *Anamnesis* quite literally means the recalling of things past.
  - 14 Nor, is it clear that clinicians themselves understand the ethical and legal ramifications and procedures surrounding "consent" forms. This past year, my spouse was briefly hospitalized for emergency, overnight surgery. She quickly hand wrote a letter assigning me guardianship of our newborn child (as I was not the infant's biological parent). When we asked the nurse to witness her signature, she refused, saying that we would have to wait until the hospital's legal department opened the following morning—far too late if my spouse died on the operating table! The surgical resident also originally refused to witness her signature despite the fact that she was willing to do so for the consent form for surgery. It was only after repeatedly explaining the nature of witnessing and of the blatant inconsistency of being willing to witness my partner's signature on one document but not on the other that the senior resident finally relented and agreed to witness the guardianship document as well as the surgical consent form!
  - 15 The study enrolled 9,000 individuals and had two phases which took place over a period of four years. The first two-year phase managed to identify several lapses in dying, hospitalized patients' communication with their doctors and explicitly designed an intervention to resolve these lacunae. The second two-year phase attempted, through a variety of tactics, to facilitate the communication between severely ill patients and physicians.  
  
During the first phase, researchers focused on medical records, looking at a patients' physiologic conditions as well as at notations about discussions between doctors and patients regarding treatment decisions and life-sustaining therapies. They also conducted interviews with patients and family members, trying to assess the severity and duration of patients' pain, their views on quality of life issues as well as their desire to access life-prolonging treatments. In the first phase, the investigators found that the hospital experience of many patients was unsatisfactory. For example, while 79 percent of Phase I patients who died had a DNR [Do Not Resuscitate] order, almost half of these were written within two days of the patient's death. Almost a third of patients expressed a desire not to be resuscitated, but slightly fewer than half of their physicians accurately knew this. Moreover, families indicated that half of dying patients who could communicate had moderate to severe pain for at least half of the time during their last three days of life.  
  
In the second phase, the researchers created a tripartite approach to the communicative lacunae between doctors and patients. Firstly, physicians were given brief reports on the prognosis of each individual patient along with the probability of whether they would survive CPR. Secondly, physicians were also given brief reports about specific patient's concerns about CPR, his/her perceptions of prognosis, his/her experience of pain and his/her desire for information. Thirdly, and perhaps most conspicuously, specially trained nurse practitioners became responsible for acting as liaisons between patients and doctors. Unfortunately, once the results of the study were tabulated, it was revealed that these interventions had no impact on patients' reported preferences regarding either resuscitation or the levels of communication with physicians (SUPPORT Principle Investigators, 1995).
  - 16 Interestingly, the reported level of patient satisfaction remained quite high through both stages of the study. This, despite the fact that patients and families reported high levels of pain and lack of communication. The results of the study indicate that perhaps generally-worded satisfaction surveys are not always good measures of quality assessment.

- 17 One need only to look at Locke, Mill and Rawls to confirm the centrality of reason in liberal theory's conception of the individual.
- 18 The SUPPORT investigators advance this conclusion: A. . . even though the targeted outcomes are objectives of much ethical and legal writing and of some explicit policy ( such as informed consent statutes, the Patient Self-determination Act, and guidelines on pain), there were no secular trends toward improvement for intervention or control patients during the 5 years of SUPPORT data collection. (SUPPORT Principle Investigators, 1995, 1596)
- 19 In *Spheres of Justice*, Michael Walzer's theory of complex equality proposes that temporary losses of equality are reasonable and even reflective of a diverse community (Walzer, 1983). According to his portrait of liberal democratic justice, we should tolerate different potencies within different social spheres. That we may experience powerlessness as a patient is more than made up by the fact that we experience authority in other social roles (i.e., as parents, teachers, entrepreneurs, etc..) While I am sympathetic with Walzer's refusal to characterize democratic societies as communities composed of carbon-copied equalities as well as with his desire to tolerate difference within egalitarian theories of justice, I am not convinced that his portrait in fact works. Like Susan Okin, I am critical of Walzer's belief in the fundamental separation of social spheres (Okin, 1989). The vulnerability or privilege of one social sphere tends to carry over into other spheres. Thus, familial, gender and economic station influences the relative power which an individual exercises within a community. Likewise, the diminution of personal agency which sick people experience when they have a disease is unlikely to limit itself to the health care setting.

Walzer argues that the powerlessness of patienthood is constrained by temporal duration. It does not have to be endured for very long and the benefits of medical expertise outweigh the loss of political power. His view can be most successfully applied to acute illnesses in which people recover quite quickly B and even here, I am not fully convinced. B However, it seems less applicable to those who have chronic ailments or to those who are fatally ill. For those people with more prolonged conditions, the impotence associated with being clinically objectified is protracted. Of necessity, the politico-medical culture becomes incorporated into everyday life. This powerlessness becomes a part of the fabric of a chronic patient's existence. It is not delimited. And, for those individuals who are dying, the medical pursuit of positivism which tends to dislocate patients' subjectivity seems a bit unjust. After all, dying is probably one of the most subjectively significant processes. It seems wrong to dismiss the political implications of the reification in medical treatment of patients who are exiting life and are at their most defenseless. (Albeit, the hospice movement has begun to make significant contributions to the care of the dying.) Walzer's conception of distinct spheres of justice seems inapplicable in both these instances. Its tolerance of powerlessness in the medical sphere is thus troubling. It is as if the private and intimate interactions of medicine are being shielded from more broad justice based critiques.

- Ainsworth-Vaughn, Nancy, (1998). *Claiming Power in Doctor-Patient Talk*. New York: Oxford University Press.
- Berg, Marc and Geoffrey Bowker. (1997). "The Multiple Bodies of the Medical Record: Towards a Sociology of an Artifact." *The Sociological Quarterly*, Summer 1997, Vol. 38, No. 3, 513-525.
- Berwick, Donald M. (1995). The SUPPORT project: Lessons for Action. *Hastings Center Report*. 25 (6).
- Bowker, Geoffrey. "Lest we remember: organizational forgetting and the production of knowledge." <http://weber.ucsd.edu/~gbowker/forget.html>.
- Bowker, Geoffrey and Susan Leigh Star. (2000). *Sorting Things Out: Classification and Its Consequences*. MIT Press.
- Broyard, Anatole. (1992) *Intoxicated by My Illness*. New York: Clarkson Potters.
- Callahan, Daniel (1995). Once Again Reality: Now Where Do We Go? *Hastings Center Report*. 25 (6), S33- .
- Davis, Marion et al. (1991). A Prospective Study of Advance Directives for Life-Sustaining Care. *NEJM* 324 , 882-888.
- Donne, John. (1623) "Devotions on Emergent Occasions." *Norton Anthology of English Literature*. Vol. I, 4th Edition. Ed. Norton. W.W. Norton & Company, 1979.
- Emmanuel, Linda (1995). Structured Deliberation to Improve Decision-making for the Seriously Ill. *Hastings Center Report*. 25 (6), S14- .
- Etzioni, Amitai. (1999) "Medical Records: Enhancing Privacy, Preserving the Common Good." *Hastings Center Report*. Mar/Apr 1999; 14-23.
- Foucault, Michel, (1994). Psychiatric Power. In *Ethic: Subjectivity and Truth*, edited by Paul Rabinow. New York: The New Press.
- \_\_\_\_\_ (1973). *The Birth of the Clinic*. New York: Pantheon Books.

## *Ethics & Medicine*

- Frank, Arthur W. (1991). *At the Will of the Body: Reflections on Illness*. Boston: Houghton Mifflin Company.
- Kleinman, Arthur. (1990) *The Illness Narrative: Suffering, Healing and the Human Condition*. New York: Basic Books.
- Koch, Robert (1932). *The Aetiology of Tuberculosis: A translation from German of the original paper announcing the discovery of the tuberculosis bacillus*. New York: National Tuberculosis Association.
- \_\_\_\_\_. (1890). Bacteriological Research. *The British Medical Journal*. 2, 380-383.
- Lo, Bernard et al. (1986). Patients Attitudes Towards Discussing Life-Sustaining Treatment. *Annals of Internal Medicine* 146, 1613-1615.
- Mansfield, Katherine. (1928). *The Journal of Katherine Mansfield*. Ed. J. Middleton Murry. New York: Knopf.
- Marshall, Patricia A. (1995). The SUPPORT Study: Who's Talking? *Hastings Center Report*. 25 (6), S9- .  
*Mastering Documentation*. (1994). Pennsylvania: Springhouse Corporation.
- Moskowitz, Ellen H. and James Lindemann Nelson (1995). The Best Laid Plans. *Hastings Center Report*. 25 (6), S3- .
- Nedelsky, Jennifer (1990). Law, Boundaries and the Bounded Self. *Representations* 30, 162-190.
- Okin, Susan Moller (1989). *Justice, Gender and the Family*. New York: Basic Books.
- Pasteur, Louis (1897). Lettre de M. Pasteur sur la Rage, 27 Decembre 1886. *Annales de L'Institut Pasteur*. Paris, 1-18.
- \_\_\_\_\_. (1886). *Resultats de l'application de la methode pour prevnir la rage après la morsure*. Paris: Gauthier-Villars.
- Peeno, Linda (2000). Managed care and the Corporate Practice of Medicine. *Trial* 36 (2).
- Sacks, Oliver. (1984). *A Leg to Stand On*. New York: Harper & Row.
- Schneider, Carl E. (1995). From Consumer Choice to Consumer Welfare. *Hastings Center Report*. 25 (6), S25- .
- Schneiderman, Lawrence et al. (1991). Effects of Offering Advance Directives on Medical Treatments and Costs. *Annals of Internal Medicine*.
- Sherwin, Susan (1992). *No Longer Patient: Feminist Ethics and Health Care*. Philadelphia: Temple University Press.
- Sontag, Susan. (2001) *Illness as Metaphor and AIDS and Its Metaphors*. New York: Picador Press.
- SUPPORT Principle Investigators (1995). A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). *JAMA* 274 (20), 1591-1598.
- Toops, Les (1998). Primary Care: Core Values: Patient Centred Primary Care. *BMJ* 31.
- Tronto, Joan (1993). *Moral Boundaries: A Political Argument for an Ethic of Care*. London: Routledge
- Walzer, Michael (1983). *Spheres of Justice: A Defense of Pluralism and Equality*. New York: Basic Books.
- Weber, Max. (1946). *From Max Weber: Essays in Sociology*. New York: Oxford University Press.
- Wilmshurst, Rea. (1995) Private correspondence and journals.

## CLINICAL ETHICS

### CASE CONSULTATION

FERDINAND D. (NICK) YATES, JR., M.D.

*The following consultation report is based a real consultation request; some details have been changed to protect patient privacy. The goal of this column is to address ethical dilemmas faced by patients, families and healthcare professionals, offering careful analysis and recommendations that are consistent with biblical standards. Column editor: Robert D. Orr, MD, CM, Director of Clinical Ethics, CBHD*

**Question:** *Is it ethically permissible to place a permanent feeding tube in this patient whose advance directive declines artificial nutrition and fluids?*

This 76 year-old woman with a past history of hypertension (treated with calcium blocker) and arterial fibrillation (an irregular heartbeat treated with Coumadin, an oral medication for anticoagulation) had a stroke 4 days ago while visiting her terminally ill daughter. She presented in the Emergency Department with right hemiplegia (paralysis of her right side) and global aphasia (inability to speak), accompanied by a slow pulse (in the 40's). Her exam and assessment on admission were consistent with a large left middle cerebral artery stroke. Her pulse rate improved with the withholding of her calcium blocker. A head CT at that time showed no acute hemorrhage, and repeat now shows a large left hemispheric ischemic stroke (lack of blood supply to most of the left side of the brain). She has been further anticoagulated with injectable heparin and is being feed through a naso-gastric (NG) tube; she has an intravenous line in place and a catheter in her bladder. She remains awake, tracks visually, and can follow simple commands. However, she has had no meaningful neurologic recovery in 4 days and is unable to swallow. Her caregivers anticipate that she will have little or no neurologic recovery, but recognize there is some uncertainty because it has only been 4 days. They have recommended placement of a PEG tube (percutaneous gastroscopically-placed gastrostomy) if long-term feeding is to be done.

There are in her chart both a Living Will and a Durable Power of Attorney for Health Care signed and witnessed 10 years ago; the latter names one of her sons as her agent. For instructions to her agent she copied the suggested option "If I suffer a condition for which there is no reasonable prospect of regaining my ability to think and act for myself, I want only care directed to my comfort and dignity, and authorize my agent to decline all treatments (including artificial nutrition and hydration) the primary purpose of which is to prolong my life."

I met with a daughter, two sons and a daughter-in-law; her other daughter is terminally ill. They report that before this stroke the patient was living alone in senior housing in a community 75 miles away and was fully functional, walking with a cane or walker, driving her car, going to church and bingo. They

describe her as a pleasant and quiet woman. Her husband died 10 years ago of cancer with painful boney metastases. During his terminal illness, they signed identical advance directives and said they wanted "no machines", but had no further discussion about specific wishes. All family members present agreed that her goal was to avoid prolongation of a painful dying process by the use of machines and tubes. They are convinced that she would choose to continue artificially administered feedings until her prognosis was very clear, perhaps for a month, but that she would not want to survive via feeding tube if she could not improve.

### **Assessment**

The patient is an elderly widow who, until recently, has enjoyed reasonably good health and an independent lifestyle. She has now suffered a severe stroke. Her family is struggling with a decision about appropriate medical care which seems to conflict with her wishes written in an advance directive.

### **Discussion**

This case illustrates the complex issues that present themselves as a health care agent makes medical decisions for the patient who cannot speak for herself. Advance directives come in two basic forms: a treatment directive (e.g., a Living Will) which specifies what treatments the patient wants, possibly coupled with some explanation, and a proxy directive (e.g., a Durable Power of Attorney for Health Care or DPA/HC) which designates an agent (proxy) to make decisions. In general, the Living Will is less useful because it is impossible to elucidate all of the possible medical scenarios, and there is no way of foretelling what sort of technological interventions may be needed or available when the document is actually executed. The DPA/HC is more flexible because it appoints an agent with broad authority to speak for the patient when she is unable to speak for herself. Since the DPA/HC may or may not give some instructions to the agent, the agent should have a good understanding of the patient's life philosophy, world view and (in so far as possible) medical preferences. In this way, the agent can make decisions using "substituted judgment" because he or she knows quite a bit about the patient, the patient's family, how the life was lived, and what might be medically preferred. The agent should be prepared to be faithful to the intent of the patient and should strongly consider recusing himself if he is unable to uphold the patient preferences.

This patient is in the 4<sup>th</sup> day following a stroke that involves a significant portion of the left half of her brain, and there has been no meaningful improvement. The doctors and family concur that the patient has lost the capacity to make decisions and that the health care agent should be allowed to speak for the patient. The advance directive authorized ". . . my agent to decline all treatments (including artificial nutrition and hydration) the primary purpose of which is to prolong my life." This notion is the crux of the ethical dilemma.

At this time, the patient needs rather uncomplicated care. The primary issue is that of fluids and artificial nutrition while allowing an appropriate period of time to observe for meaningful neurologic recovery. Artificial nutrition is presently provided by NG tube, commonly used short term, but its use may be limited by side-effects such as irritation by the tube, sinusitis, and aspiration. Generally, if artificial feeding is planned for more than a couple of weeks, a PEG tube is used. In addition placement in a long term care facility (thereby optimizing OT, PT and post-stroke recovery) may be predicated upon the method of nutritional management. Some facilities may only accept a patient in this medical condition if a PEG tube in place. This patient's advance directive appears to decline both NG and PEG feedings. The family believes, however, that she would choose to continue artificial feedings until her long-term prognosis is clear. They have identified the time period of approximately 1 month to observe for neurologic improvement and a more identifiable prognosis, and they therefore believe placement of a PEG tube is necessary.

### Recommendations

- 1) As the prognosis of the patient's neurologic condition is unclear, it is ethically permissible to insert a PEG tube for a pre-determined time period with the intent of observing for neurologic improvement. A month may be an unreasonably short period of time, and this issue should be discussed with an individual who has expertise in post-stroke care. After this period of time, if the conditions of the Advance Directive are met, then the artificial nutrition may be discontinued.
  
- 2) Continued care for the patient and communication between family members and the health care team remains pivotal since a chronic illness poses an immense strain on the family.

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### Follow-up (editor):

Six weeks later, a phone call to the nursing home finds that the patient has had little neurologic improvement, but she has recovered the ability to swallow. She is now taking a pureed diet by mouth and the PEG tube has been removed.

Fourteen months later, she has had no further improvement, but appears to have settled into the nursing home setting. *E&M*

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*Ethics & Medicine*



# DEATH OF JOHN PAUL II AND THE BASIC HUMAN CARE FOR THE SICK AND THE DYING<sup>1</sup>

BY JUAN R. VÉLEZ G.

## Abstract

*The death of Terri Schiavo by starvation and its sanction by some United States Courts indicates the alarming revival of the eugenics and euthanasia movement. From the legal sanction of physician-assisted suicide, the euthanasia movement now tries to advance the legal protection for "mercy killing."*

*Terri was diagnosed with persistent vegetative state, a term that is outdated, vague and imprecise and that likens a human being to a vegetable. Medical literature indicates that patients with so-called "persistent vegetative state" can recover, and that they do experience pain.*

*The euthanasia movement, linked to eugenics in its origin and present day influence in bioethics espouses the Nazi notion of "lives not worth living," unlimited patient autonomy, and philosophical utilitarianism.*

*John Paul II countered the eugenic philosophy with the classical Western concept of man as the image and likeness of God, responsible for the care of himself and society as a whole. He taught in writing and by example that food and water are basic human care that every person should receive. In the last days of his life he showed a judicious use of proportionate or ordinary means to maintain life. He chose to forego disproportionate medical treatment when there was no reasonable hope of recovery. At that point he continued to receive ordinary medical care, together with basic human and spiritual care.*

In March, a woman was starved to death in a Florida Hospice. Some considered it a merciful death or to be precise "mercy killing." A growing number of directors in the movie industry and newspaper publishers are embracing the practice of euthanasia in the Western World enforced on Terri Schiavo in Florida.<sup>2</sup> The Academy award winning movie *Million Dollar Baby* suggests that euthanasia is the best solution to what was perceived as a sorrowful existence. This year the European Film awards went not accidentally to another movie espousing mercy killing as a reasonable and necessary practice in society.

Suicide, physician-assisted suicide, and involuntary termination of people's lives are not new in the history of mankind. What is novel, and alarming, is the increasing legitimization and legalization of practices that are contrary to the Western tradition of the person's obligation not to harm himself, his duties of justice towards God and others, and the good of society.<sup>3</sup> Furthermore, the case of involuntary euthanasia constitutes a practice that is equivalent to homicide. The latest developments are now the withholding of food and water to procure such death, and the extermination of children with malformations.

## **Struggle Concerning Euthanasia in the United States**

The death of Terri Schiavo by starvation over 13 days occurred on the same week as the death of John Paul II. They had very different medical conditions. Terri was in a state of altered consciousness for the last fifteen years of her life, while the pope suffered for many years with Parkinson's Disease. Their illnesses and deaths were different, yet related because one, who was not dying, was killed by the deliberate deprivation of ordinary human care while the other was given the care that we all expect to receive when death approaches us.

The news media wrongly insisted on Terri's condition of "persistent vegetative state" and the judgment that her life was worthless. Terri Schiavo was a victim of a culture that has come to uphold personal autonomy as its highest good. Unable to express herself verbally or act freely, completely dependant upon others for her care and apparently useless to society, she was considered a "vegetable" and her life was deemed unworthy of existence. She did not meet the utilitarian characteristics for a life worthy of existence.

Despite the attempts of the executive branch of the Florida state government as well as the Federal Government and both the state and federal legislatures to defend her right as a disabled person, a few state and federal judges concluded that Michael Schiavo spoke on behalf of his wife, and he claimed she did not want to live in such a condition. There was no proof that these were Terri Schiavo's wishes, and the judges ignored Terri Schiavo's parents, Bob and Mary Schindler, who wanted to take complete responsibility for her care.

The debate surrounding the case of Terri Schiavo was not about foregoing the use of extraordinary measures such as the use of mechanical respirators or dialysis machines to sustain life, but rather the administration of food and water to a chronically ill patient unable to communicate in the ordinary manner.<sup>4</sup> The real issue, then, was about the legitimization, not simply of physician-assisted suicide, but involuntary euthanasia. The apparent victory of her husband and the euthanasia movement was made possible by the continuing usurpation of democratic power by United States courts. A strong argument can be made that Terri's rights under the "due process" and "equal protection" clauses of the Constitution were denied.

Physician-assisted suicide has been sanctioned by law in the Netherlands and Belgium, and it is practiced illegally in some parts of the United States, Australia and New Zealand. Following a ballot initiative in 1994, a law was passed in Oregon allowing for physician-assisted suicide.<sup>5</sup> It was appealed as far as the Supreme Court, which found no federal constitutional right for physician-assisted suicide, but did not address the rights under individual state constitutions.

As a consequence, bills in almost half of the states have attempted to interpret this as including a state right to physician-assisted suicide. All have failed, but some have failed by increasingly smaller margins. These bills were presented despite opposition by the American Medical Association. At the same time bills have been introduced into almost twenty state legislatures to ban so-called "death with dignity" bills, however only a handful have passed.

## **Vegetative State, Outdated and Vague Term**

In the early 1970's the term "persistent vegetative state" was coined for patients who suffered a state of unresponsiveness to verbal commands but who opened and closed their eyes spontaneously. The condition was termed "persistent" although it has been shown that some patients do recover their health and consciousness.<sup>6</sup>

It has also become increasingly clear that this is an outdated medical term that is as vague, misleading, and pejorative as such expressions as grand mal or epilepsy. The connotation of "vegetable-like" contributes to a self-fulfilling prophecy where "the prognosis is poor, therefore no treatment is given, therefore the prognosis is poor".<sup>7</sup> Neurology shows that there is a variety of conditions in which patients have differing degrees of altered consciousness with coma as one of the most severe alterations.<sup>8</sup>

In addition, the words "vegetative state" should no longer be used because a human being should not be compared to a vegetable. A human is always a human, never a vegetable. This terminology and a superficial approach to patients have led to the belief that patients with altered consciousness do not experience pain. On the contrary, neurological research in the last decade has begun to show that the perception of pain involves the interaction to the sensory-somatic cortex, the brain stem and the limbic system.<sup>9</sup> In other words, patients with severe brain damage that are in so-called "vegetative states," may be experiencing pain because pain is not only registered by the cortical or higher brain.

EEG studies performed on patients with this "diagnosis" who are undergoing dental surgery have shown similarity in response to painful stimuli with that of normal persons.<sup>10</sup> Furthermore, different subsets of patients, until now called patients with a "vegetative state," have been identified. Among one of these groups it is possible that there is a disconnection between the cortical and brain stem structures in which case patients cannot express pain that is perceived.

As in the case of abortion of a human fetus, the unproven assumption that patients in "vegetative states" feel no pain is used as a justification for the suspension of medical treatment and sometimes ordinary care. Physicians and nurses are bound by the mission of their profession to 'seek the good of their patient' and "never to do harm to anyone".<sup>11</sup> They must refrain from causing pain to the patient unless it is an unintended consequence of a treatment with a hopeful outcome. A physician should not even treat patients disrespectfully, let alone actively cause their death. The apparent good sought by ending the life of Terri Schiavo or persons in her condition is the relief of suffering, but the reality of euthanasia by dehydration is a slow, inhumane death. We might also note that the justification for ending the life of such patients—their release from suffering—flatly contradicts the premise these patients feel no pain. If they feel no pain, whose suffering does their death relieve?

## **John Paul II's Teaching and Example**

During the last year of his life, Pope John Paul II gave an example of accepting illness with serenity and courage. He portrayed the role that the elderly have assumed in society despite their lack of health and physical strength. However, in the final weeks of his life, John Paul II offered the world a lasting testimony of the sanctity of human life and an example of the proportionate medical treatment and basic human care due to gravely ill human beings.

On February 24, he was rushed to the Gemelli Hospital with respiratory distress due to soft tissue swelling in the upper respiratory tract and required an emergency tracheotomy to relieve his breathing. After days of treatment and rest at the hospital, he returned on March 13 to his home at the Vatican with a desire to continue to work and meet with the people under his care.

His health continued to deteriorate over the next two weeks. By March 30, the Pope accepted the use of tube feeding under the care of his physician, Dr. Renato Buzzonetti. As a result of a urinary infection, he developed a generalized infection called sepsis and, in consequence, kidney failure and cardiac arrest. During this time it appears that he remained conscious. With the help of his aids, he presumably decided - or it was decided for him, in accordance to his moral teaching - that no heroic life sustaining measures be taken, in contrast to what had been the case for a short time a few weeks prior.

John Paul II was given medical treatment consisting of at least antibiotics and most likely oxygen by means of a small tracheotomy collar. At the same time, he received palliative care for a fever, hydration, feeding and the basic human care and affection that all human beings need and deserve. He died on the evening of April 2nd of cardiovascular collapse from septic shock. Dr. Buzzonetti told *La Repubblica* newspaper that John Paul "passed away slowly, with pain and suffering which he endured with great human dignity."

All of this basic human care was in keeping with a discourse that he made to an international congress on "Life Sustaining and the Vegetative State" at the Vatican City.<sup>12</sup> In this discourse, John Paul II stated that hydration and nutrition are ordinary and proportionate care that are morally obligatory. He affirmed that this care is ordinary human care; it should not be considered medical care even if it is provided through a feeding tube. His teaching with regard to conditions of altered consciousness applies to the care that all human beings, regardless of their medical condition, should receive.

John Paul II reminds us that all treatment of patients, whether involving extraordinary or ordinary medical measures, or simply basic human care, is first and foremost the treatment and care of *persons*. He wrote: "[I] feel the duty to reaffirm strongly that the intrinsic value and personal dignity of every human being do not change, no matter what the concrete circumstances of his life or her life. *A man, even if seriously ill or disabled in the exercise of his highest functions, is and always will be a man, and he will never become a "vegetable" or an "animal".*<sup>13</sup>

Despite the Pope's medical condition, the end-of-life care given to him was an indirect affirmation of his 2004 teaching on the hydration and nutrition of patients with altered states of consciousness. In that address, he extended

the presumption in favor of the provision of food and water for terminally ill patients to those in the so-called “vegetative states.”

A public debate regarding the ethical obligation to provide hydration and nutrition to terminally ill patients (for example patients with end stage cancer or severe multi-organ failure) led United States bishops and theologians to the conclusion that it was the duty of caregivers and physicians to provide this basic care for patients. In 1986, the United States Catholic Bishops Conference published a statement that read: “Since food and water are necessities of life for all human beings and can generally be provided without the risks and burdens of more aggressive means for sustaining life, the law should establish a strong presumption in favor of their use.”<sup>14</sup>

On March 25, 1995, John Paul II reiterated the Catholic Church’s teaching on euthanasia. He wrote: “Here we are faced with one of the more alarming symptoms of the ‘culture of death,’ which is advancing above all in prosperous societies, marked by an attitude of excessive preoccupation with efficiency and which sees the growing number of elderly and disabled people as intolerable and too burdensome.”<sup>15</sup> Then, in the strongest language possible short of a formal declaration of a new dogma, he taught that euthanasia is a grave violation of the law of God because it is the deliberate and morally unacceptable killing of an innocent person.<sup>16</sup> “Society must not permit that a person’s life or death hangs in the balance because of the way others feel about them. All human life must be defended and protected in law, not for what it means to others, but for what it is in itself.”<sup>17</sup>

A salient point of John Paul II’s March 2004 address is that the principle of universal human dignity applies to *all* patients, and not just those with end stage illnesses. This stands in stark contrast to the views of philosophers like Ronald Dworkin, who contend that patients with severe brain injury who are apparently unable to communicate in ordinary ways are no longer human beings, but vegetables.<sup>18</sup>

In the same discourse, John Paul II reasserted an important distinction for the care of patients, namely the division of treatment into ordinary or proportionate on the one hand and extraordinary or disproportionate on the other. He explained that a patient is not obliged to accept or to be given extraordinary care at all times. This type of care can be discontinued when there is no reasonable expectation of improvement or it causes a significant burden on the patient and to those who care for him. The medical treatments given to people that are life-sustaining treatments should have an expected benefit that is proportionate to the possible pain, harm and cost that they require.

## **Origins of Euthanasia and Links to Eugenics Movement**

Today, this principle of respect for human life is most flagrantly violated in the Netherlands, where, as mentioned above, euthanasia was legalized in 2002, allowing adult patients suffering from incurable diseases to request assisted suicide. Teenagers under the age of 16, can, with the approval of parents, also request physician-assisted suicide. At present approximately 3% of deaths in Holland are due to physician-assisted suicide. There is an ongoing movement

to legalize euthanasia practiced on children. Gronigen Academic Hospital is openly practicing this with the knowledge of the Dutch Government.

This is the latest manifestation of the well-known Nazi eugenics movement involving physicians. The death camp exterminations were preceded by the practice of killing children born with malformations, followed by the termination of patients with mental handicaps. A significant part of the medical establishment in Nazi Germany accepted the commission of this killing completely at odds with the purpose of the medical profession. The Dutch medical association of the time opposed it. Today we are in the midst of a revival of eugenics and infanticide that is clothed in legal theory of rights, choice, freedom and privacy.<sup>19</sup>

The Eugenics movement for the purification of the Arian race began in the mid 1800s in England and Germany and soon was present in the United States.<sup>20</sup> The philosophical position in favor of suicide, physician-assisted suicide, and "mercy killing" of others are based on eugenics and a utilitarian philosophy, and justified by arguments on quality of life, the relief of pain, and the determination of moral status of persons.

The eugenics argument is related to the social Darwinist theory of the survival of the fittest. Not all humans have the same capacities and some are a burden to society. They create problems and should not be allowed to reproduce or drain its resources.<sup>21</sup> Although few people would openly ascribe to such a blatantly cruel treatment of people, the rising national health costs, the change in the configuration of families, and an increasing rejection of core moral values explain a wider acceptance of the concept of "lives not worth living."

## **The Utilitarian Worldview and the Principle of Personal Autonomy**

One of the justifications for euthanasia is the philosophical position known as utilitarianism. Strictly speaking, utilitarianism seeks to bring about whatever outcome maximizes that which is perceived as a good or intrinsic value. Since modern philosophers cannot agree on how to select between many kinds of intrinsic value, the utilitarian theories of Jeremy Bentham and John S. Mill have been superseded by preference utilitarianism. This moral theory holds that to determine maximal value and consequently where rightful action lies, one must appeal to individual preferences. It seeks to maximize preferences, as the ultimate arbiters of what is good or valuable.

The practical effect of such a view is that people who are unable to act autonomously are not recognized as moral persons and are therefore deemed expendable by society. Those who are unable to act autonomously are denied their human rights. Peter Singer claims that infants are not persons so that they do not have the moral right to live. He has stated that parents should be able to end the life of babies with severe disabilities within the first month of life, and he has expanded this to include other infants such as those with hemophilia.<sup>22</sup> Despite his efforts to disassociate his position from Nazi eugenics he fails; at the start, Nazi propaganda also argued for the relief of the suffering of disabled children.

With regards to the infanticide of newborns with hemophilia Singer writes: "When the death of a disabled infant will lead to the birth of another infant with better prospects of a happy life, the total amount of happiness will be greater if the disabled infant is killed. The loss of the happy life for the first infant is outweighed by the gain of a happier life for the second. Therefore, if the killing of a hemophiliac infant has no adverse effect on others it would...be right to kill him."<sup>23</sup> This utilitarian calculus includes the fortuitous relationship between the death of one and the life of the other, the measurement of human happiness, and the legal endorsement of premeditated murder.

In the 1970s the term "bioethics" was coined for the study of ethical decisions regarding the care of patients. In a break with long standing values about actions evaluated as good or bad, the criteria for ethical decisions was replaced by the weighing and balancing of the principles of autonomy, non-maleficence, beneficence and justice, as articulated by Tom Beauchamp and James Childress.<sup>24</sup> The system they proposed to govern moral judgments has no overriding principle or hierarchy, and despite adjustments over the years inevitably leads to a conflict of principles. Furthermore, its method for arriving at these judgments is the result of intuitions rather than reasons.<sup>25</sup>

Beauchamp and Childress explain that from a utilitarian perspective, "no rule is absolutely wrong in itself, and no rule in the system of rules is absolute and unrevisable."<sup>26</sup> According to this theory even rules against killing may be revised or overturned. In the ensuing decades the principle of autonomy, originally stemming from the principle of respect for persons, was reduced to that of informed consent and became the moral justification for any choice. Many academics who reject the moral and religious values of Western Civilization have made these criteria a new religion that they have imposed on the whole of society.

Patient Autonomy has become for some a reformulation of moral relativism.<sup>27</sup> It replaces objective moral standards of good and evil with the notion that the patient alone is to decide what is good.<sup>28</sup> According to this principle the patient decides what is good. Those patients who decide that they do not wish to suffer any longer have the right to end their lives and to have doctors end their lives. Ronald Dworkin, in his book *Life's Dominion: An argument about Abortion, Euthanasia and Individual Freedom*, went further by arguing that people's free choices in matters of life and death must be accepted by society and tolerated by those who disagree if society is not to become totalitarian.<sup>29</sup>

We can of course agree that the principle of autonomy, as an *instrumental* good, plays a vital role in safeguarding the respect due to each person. Patients themselves, cognizant of their own personal circumstances and sense of vocation, are usually in the best position to decide what objectively is right for them to do.<sup>30</sup> But in respecting patient autonomy, we should bear in mind the difference between not forcing treatment on someone and blindly carrying out every autonomous choice, such as a decision to commit suicide.

By asserting his own criteria—namely, near limitless freedom and control of one's life—as the measure of the "good" in a pluralist society, and rejecting a priori the criteria derived from religious beliefs and natural law, Dworkin and others like him enshrine eugenics principles in United States court decisions,

the general media, government policy decisions, hospital ethics committees, and medical education. But this exaggerated notion of patient autonomy, ironically can and recently has, in some countries lead to state control of patient's lives. Once the notion of "lives not worth living" has been sanctioned by society, incompetent patients suffer the risk of having their lives terminated by doctors, lawyers and family members. The instrumental good of autonomy has been turned against their own intrinsic good as members of society.

In the end, the notion of absolute control over life is only an illusion. As writer Janet Madigan states, "life is the most fundamental right. It is only the basis of every other good, it also, by its very nature, delineates the limit's of man's freedom—for however much we may like to think of ourselves as autonomous, and however far we may think we can carry out our conquest of nature, the one thing we cannot have ultimate control over is life itself. Nobody can choose not to be born, nobody can choose not to die. Life itself is the limit over our autonomy. Thus it makes no sense to hold autonomy as a higher value than life."<sup>31</sup>

### **Human Rights and John Paul II's Legacy**

Euthanasia, like abortion, is a violation of human rights.<sup>32</sup> It assumes that human persons do not have an inherent right to life based on their nature as members of the human race. According to those who hold eugenic views, one's moral status depends upon the possession of certain characteristics. This is an arbitrary assignation of personhood that changes with the tastes, interests, and economic considerations of the ruling body. Therefore, human life is measured in a purely subjective manner, often from a philosophical or economic perspective. The result is the conclusion that only some people are "moral persons." Some cease to be persons when they grow old or incapacitated; some are simply "unworthy of life."

This outright abuse of human rights is tolerated by a romantic notion of freedom and autonomy, and a simplified vision of human suffering devoid of a holistic approach to suffering.<sup>33</sup> As John Donne famously intoned, "No man is an island."<sup>34</sup> No one suffers alone. When a person suffers, he does so as a whole human being, body and soul connected to his family, friends and society. Suffering bereft of its spiritual and moral capacity to engender love can become absurd and lead to despair.

John Paul II was aware that, in the last few years of his life, his Parkinson's, his hip surgery, and other ailments were a source both of suffering and spiritual energy for him and for those he served. In a letter to the elderly and addresses to the sick he reminded them of the redemptive meaning that can be given to human suffering. He urged families, health providers and all members of society to care for those suffering so that they do not feel alone, worthless, and guilty of being a burden.

The "final solution" advocated by proponents of euthanasia, whether it be physician-assisted or the involuntary, now practiced on children and elderly persons, is their removal of some from society without their consent or under economic and moral pressure. The experience of euthanasia in the Netherlands



indicates what was foreseen, namely that so-called "voluntary euthanasia" leads inevitably to involuntary euthanasia. Human rights are abrogated; physicians, nurses, hospital administrators, politicians, and even family members begin to decide who should live. When human rights are considered a benefit granted by society that are conferred or removed, the whole order of civil and human society flounders.

John Paul II explained that even when euthanasia is not motivated by selfishness in the care of someone who is suffering, it must be called a "false mercy" and even a "perversion of mercy." "True 'compassion' leads to sharing another's pain; it does not kill the person whose suffering we cannot bear. Moreover, the act of euthanasia appears all the more perverse if it is carried out by those, like relatives, who are supposed to treat a family member with patience and love, or by those, such as doctors, who by virtue of their specific profession are supposed to care for the sick person even in the most painful terminal stages."<sup>35</sup>

According to the Pope, the injustice becomes more serious when a person has not requested or consented to euthanasia and it takes the form of murder. Those who are strong and called to protect the weak in society become unjust arbiters with power to decide who ought to live and who ought to die. With this the sense of justice, mutual trust and the basic of authentic interpersonal relationships in society are undermined.<sup>36</sup>

In the same encyclical letter, John Paul II explained in detail the Judaeo-Christian understanding of man made in the image and likeness of God, with an immortal soul, and a life that is sacred because of its intimate connection with its Maker. Human life should be the object of the respect, service, affection, and charity of others and never of harm. He reminds us of Christ's words: "Amen, I say to you, whatever you did for one of these least brothers of mine, you did for me" (Mt 25: 40).

The Legacy of John Paul II is a spiritual, religious, and human one. He is rightly acclaimed by men and women throughout the world as a "Champion of human rights." He spoke on behalf of those denied just wages or deprived of political freedom; he defended children, women and men exploited for all types of reasons. In all this he maintained that a just and human society must defend its weakest members, the unborn and the elderly and the sick. Without respect for these a society becomes totalitarian; it loses its human course.

Through his last weeks of life, he left for the world a visible example of the proper use of medical care, receiving it when commensurate with the hope of benefit, and foregoing extraordinary measures when these were clearly not in proportion to the expected outcome. He showed us the importance of ordinary medical care with antibiotics and of basic human care with nutrition through a feeding tube.<sup>37</sup> When he suffered multi-system organ failure, medical treatment that was disproportionate with his overall condition was not sought.<sup>38</sup> He lived and died according to the truths that he had taught: "In such situations, when death is clearly imminent and inevitable, one can in conscience refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted."<sup>39</sup>

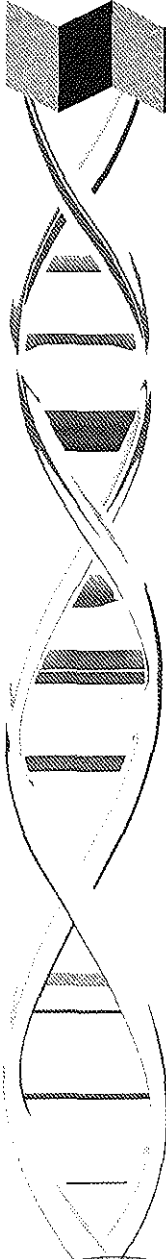
As a pediatrician and friend Dr. Michael Fragoso puts it so well: “the Holy Father taught us how to die. He suffered with dignity with Parkinson’s disease. He made use of modern medicine to allow him to continue his ministry but not prolong his life artificially. In the end when he saw that death was near he patiently waited in his home. Supported by his household, having set his private affairs in order and having provided for an orderly succession, he retreated in prayer and waited, as someone put it, ‘for the Lord to open the door’: In peace, master of his faculties, surrounded by loving, supporting arms. Would that we all may have such a death!” E&M

## Endnotes

- 1 I wish to acknowledge the insight and assistance of Susan Ridlen, RN who is a dedicated ICU nurse in Boston, Massachusetts, and of Christopher Tolleisen, professor of Philosophy at the University of South Carolina.
- 2 “By euthanasia is understood an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated”. *Declaration on Euthanasia, Vatican Documents, Sacred Congregation for the Doctrine of the Faith, May 1980.*
- 3 With the exception of Stoics and Epicureans, Western thought on suicide, from Plato, Aristotle, Augustine, Aquinas up to Kant was opposed in varying degrees to the idea of suicide. In his 1783 essay “On Suicide”, David Hume begins a new trend with his rejection of Aquinas’ natural law arguments.
- 4 Persons are not morally obligated to always use extraordinary measures also called disproportionate to sustain life when there is very little hope of improvement or recovery. “Euthanasia must be distinguished from the decision to forego so-called “aggressive medical treatment”, in other words, medical procedures which no longer correspond to the real situation of the patient, either because they are by now disproportionate to any expected results or because they impose an excessive burden on the patient and his family. In such situations, when death is clearly imminent and inevitable, one can in conscience “refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted”. John Paul II, *The Gospel of Life*, March 25th, 1995, n. 65.
- 5 United States Supreme Court will begin to hear oral arguments in October 2005, on whether to overturn a Ninth Circuit ruling that upholds the Oregon legislation.
- 6 H. S. Levin, C. Saydjari, et al., “Vegetative State After Closed-Head Injury: A Traumatic Coma Data Bank Report,” in *Archives of Neurology*, Vol. 48, June 1991: pp. 580-585.
- 7 Keith Andrews, “Managing the persistent vegetative state: early, skilled treatment offers the best hope for optimal recovery,” in *British Medical Journal*, Vol. 305, August 1992, p. 486.
- 8 A study of 80 patients showed recovery of 38 patients after 12 months. The best predictor of poor prognosis was MRI evidence of lesions in the corpus callosum and brain stem. However, patients were only followed up for one year. A. Kampfl, E. Schmutzhard, G. Franz, “Prediction of recovery from post-traumatic vegetative state with cerebral magnetic-resonance imaging” in *The Lancet*, Vol. 351, June 1998, pp. 1763-1768.
- 9 D. Alan Shewmon, “A critical analysis of conceptual domains of the vegetative state: Sorting facts from fancy” in *NeuroRehabilitation*, Vol. 19, 2004, pp. 343-347.
- 10 J.J. Pandit, B. Schmelzle-Lubiecki, M. Goodwin et al., “Bispectral index-guided management of anaesthesia in permanent vegetative state” in *Anaesthesia*, Vol. 57, 2002, pp. 1190-1194.
- 11 The Hippocratic Oath reads: “I will prescribe regimens for the good of my patients according to my ability and my judgement and never do harm to anyone. To please no one will I prescribe a deadly drug nor give advice which may cause his death.” [http://en.wikipedia.org/wiki/Hippocratic\\_Oath](http://en.wikipedia.org/wiki/Hippocratic_Oath).
- 12 John Paul II, “On Life-Sustaining Treatments and the Vegetative State, Scientific Advances and Ethical Dilemmas” in the *National Catholic Bioethics Quarterly*, Autumn 2004, pp. 573-576.
- 13 *Ibid*, p. 3.
- 14 Statement on Uniform Rights of the Terminally Ill Act, NCCB Committee for Pro-Life Activities, June, 1986, *Origins*, Vol. 16, p. 222.
- 15 John Paul II, *The Gospel of Life*, March 25th, 1995, n. 64.
- 16 *Ibid*, p. 65.
- 17 *Ibid*.
- 18 After describing Nancy Cruzan as someone who was like a vegetable for seven years, and medical treatment in intensive care units, Dworkin writes: “We all dread that. We also dread—some of us dread it more—life as an unthinking yet scrupulously tended vegetable”, Ronald Dworkin, *Life’s Dominion*, New York, 1993, p. 180.
- 19 David P. Mortimer, “The New Eugenics and the Newborn: The Historical ‘Cousinage’ of Eugenics and Infanticide” in *Ethics & Medicine*, Vol. 19:3, Fall 2003, p. 156.

- 20 Janice Chik, "Euthanasia and Physician-Assisted Suicide: A Virtue Ethics Approach", Senior Theses, Princeton University, 2005, See Ch. 1, *History of the Contemporary Debate: Euthanasia in Victorian England and 20th Century America*, pp. 17-32.
- 21 "At the same time, Francis Galton (Charles Darwin's cousin) introduced his notions of a "scientific priesthood," which also helped to shape the intellectual debate over suicide and euthanasia during the latter decades of the 19th century. Galton advocated a kind of positive eugenics, outlining strategies to improve the quality of the gene pool—an inheritance that would be bestowed upon succeeding generations", *Ibid*, p 22.
- 22 Peter Singer, *Practical Ethics*, 2nd Ed., Cambridge University Press, 1933, p. 186.
- 23 *Ibid*.
- 24 Tom L. Beauchamp, James F. Childress, *Principles of Biomedical Ethics*, 2nd Ed., Oxford University Press, 1983
- 25 Tom Tomlinson, Balancing Principles in Beauchamp and Childress, [www.bu.edu/wcp/Papers/Bioe/BioeTom1.htm](http://www.bu.edu/wcp/Papers/Bioe/BioeTom1.htm), pp. 1-6.
- 26 Tom L. Beauchamp, James F. Childress, *Principles of Biomedical Ethics*, 2nd Ed., Oxford University Press, 1983, p. 32.
- 27 In 1870, Samuel Williams, a school teacher in Birmingham England wrote an essay entitled "Euthanasia" in which, based on the idea of personal autonomy he argued for providing patients with incurable illness chloroform for quick and easy death.
- 28 Dr. Edmund D. Pellegrino argues that patient's wishes cannot automatically trump the physician's competence, discretion and moral obligations. See Pellegrino, Edmund D, Patient Autonomy and the Physician's Ethics, in *Annales CRMCC*, tome 27, n. 3, April, 1994, pp. 171-173.
- 29 Wesley J. Smith, *Culture of Death: The Assault of Medical Ethics in America*, Encounter Books, 2000, xi-xii. Smith comments on the influence of Dworkin's book on a 1999 Montana Supreme Court decision, James H. Armstrong, MD v. The State of Montana, which relied heavily on Dworkin's book and significantly diminished the state's right to regulate the practice of medicine by allowing patients almost anything they wish if a health care professional is willing to do it.
- 30 Boyle Joseph, Limiting Access to Health Care: A Traditional Roman Catholic Analysis, in "Allocating Scarce Medical Resources: Roman Catholic Perspectives", Engelhardt, H. Tristram Jr, Cherry, Mark J., eds, Georgetown University Press, 2002, p. 83.
- 31 Janet Holl Madigan, *Being Human, Being Good: The Source and Summit of Universal Human Rights* (Dissertation submitted to the Faculty of the Graduate School of the University of Maryland), College Park, 2004, p. 345.
- 32 The eugenics and euthanasia movements developed together practically as one movement based on a utilitarian philosophy of life and a Darwinian conception of the human being.
- 33 Psychiatrist Joanne Angelo explains that the 2-4% of terminally ill patients who commit suicide are usually seriously depressed. She writes that: "Clinicians experienced in hospice and palliative care have learned how to treat and prevent depression in the terminally ill and how to help patients and families live full and meaningful lives during the course of a terminal illness." J. Angelo, "Depression and Assisted Suicide in the Terminally Ill" in *The National Catholic Bioethics Quarterly*, Autumn 2001, Vol. 1, No. 3, p. 310.
- 34 "All mankind is of one author, and is one volume; when one man dies, one chapter is not torn out of the book, but translated into a better language; and every chapter must be so translated...As therefore the bell that rings to a sermon, calls not upon the preacher only, but upon the congregation to come: so this bell calls us all: but how much more me, who am brought so near the door by this sickness....No man is an island, entire of itself...any man's death diminishes me, because I am involved in mankind; and therefore never send to know for whom the bell tolls; it tolls for thee." John Donne, Meditation XVII, <http://isu.indstate.edu/ilnprof/ENG451/ISLAND/>
- 35 John Paul II, *The Gospel of Life*, March 25th, 1995, p. 66.
- 36 *Ibid*.
- 37 John Paul II received the nursing care, human companionship and spiritual assistance and love that all persons need in times of illness and especially at the end stages of life.
- 38 *The Gospel of Life* states that "Euthanasia must be distinguished from the decision to forego so-called "aggressive medical treatment", in other words, medical procedures which no longer correspond to the real situation of the patient, either because they are by now disproportionate to any expected results or because they impose an excessive burden on the patient and his family", p. 65.
- 39 *Ibid*.

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## BOOK REVIEWS

### **In the Wake of Terror: Medicine and Morality in a Time of Crisis**

Jonathan D. Moreno, Ed.

Cambridge, MA: MIT Press, 2003

ISBN 0-262-13428-4

Much has been written since 9/11 dissecting events and lessons learned to aid future planning, but little discussion has been devoted to bioethical issues. *In the Wake of Terror* acknowledges that bioethical norms in extreme circumstances post-attack may differ from those in normal daily life. Therefore, there is a need to develop ways of responding ethically after these events. A continual theme throughout is the need to analyze these issues and their underlying values before attack and to develop and build consensus between those involved in the aftermath, including the public.

*In the Wake of Terror* is the seventh volume in the Basic Bioethics Series edited by Glenn McGee and Arthur Caplan. Among its twelve authors are such well-known ethicists as George Annas, Arthur Caplan, and James Childress. In four major sections (public health [PH], resource allocation, health care workers and industry obligations), the authors outline familiar bioethical issues and apply them to massive emergencies.

The four chapters devoted to PH focus on previous research abuses and the pros and cons of the recently proposed Model State Emergency Health Act (MSEPHA). Chapter one discusses how "Official secrecy, vulnerable populations, and the terrors of both disease and war make for a perilous combination" (p. 12-13), using examples from the World War II era, and the need to insure such abuses are not repeated. The second chapter outlines the MSEPHA, drafted in the wake of 911, as a comprehensive guideline for crafting PH laws for both the WOT and the threat of emerging infectious diseases, and discusses the advantages of and individual protections in the Act. George Annas, in chapter 3, argues against the MSEPHA believing it encroaches on human rights and that its language presents PH authorities as the "good guys" and the public as the potentially non-compliant "enemy." He compares the MSEPHA and its adverse impact to situations, such as the Guantanamo detainment of Iraqis, where abridgement of human rights resulted in adverse publicity and loss of respect for the United States. The last chapter of this section outlines the history of PH controls and authorities. It supports Annas' views, although the author acknowledges that other approaches to control outbreaks of virulent contagious diseases may be inevitable.

The remaining three sections of two chapters each touch on other bioethical issues that must be addressed in pre-attack preparations.

## *Ethics & Medicine*

Chapters five and six deal with resource allocation. Chapter five provides an excellent discussion of triage, its rationale and justifications. It presses for public participation and cooperation as an essential in designing policies, priorities, and protocols for massive emergencies. Chapter six distinguishes disaster triage from clinical and battlefield triage. It recommends a decentralized approach to care in catastrophes based on neighborhood treatment centers with pre-assigned medical staffs and sheltering-in-place.

Section III focuses on ethics for emergency health professionals in time of crisis and on universal access. Chapter seven recommends a global ethical assessment of medical ethical issues in massive emergencies and how they apply to health care workers. The next chapter views the WOT as a golden opportunity for restructuring the US medical system to provide universal access and to incorporate disaster response. It argues forcefully against the Emergency Medical Treatment and Active Labor Act (EMTALA), citing its adverse affects on emergency rooms.

The fourth section on industry deals with pharmaceutical industry ethics and the need for common goals and a systems approach to organizing the clinical and PH systems for response to future massive emergencies.

The final section deals with research and genetics. It recommends central coordination of post-disaster studies to minimize overlap and eliminate excessively burdensome studies. It identifies concerns related to study participants including informed consent, terror victims as a potentially vulnerable population, and possible re-traumatization during participation. The risks of genetic knowledge and procedures are dealt with in the final chapter, as is the fact that genetic knowledge can benefit both terrorists and defenders, depending on how it is used.

*In the Wake of Terror* provides a useful outline of ethical issues in emergency health care and crisis response. It addresses concerns with which most Christian bioethicists would agree, including the concern for proper selection and protection of human subjects, the wisdom of pre-attack planning and public participation in designing a response to terrorist attack, the need for an effective PH system, and wise allocation of limited resources. However, the book raises more questions than it answers. It would best serve as an ethical primer for planners, rather than a comprehensive, systematic guide to solutions. As in most collections, there is significant overlap in the chapters within a section. This might have been ameliorated by additional editing, but has the benefit of making each chapter a "stand alone" piece. Section I is primarily a liberal expose on PH issues. It opposes mandatory PH measures as violations of human rights with little balance from other positions. Chapter eight is a seemingly opportunistic and weakly-argued push for a health care system which ensures universal access. The remainder of the book is more balanced and beneficial in thinking through issues and potential solutions. *In the Wake of Terror* is fairly brief, easily read, well-referenced, relatively brief (218 pages), and well-indexed. I hope, however, that a similar volume might be developed from other perspectives to ensure a more balanced approach to these ethical issues.

**Sharon A. ("Shari") Falkenheimer, M.D., M.P.H.,** is President of Bioethics & Medicine, Inc., San Antonio, Texas, USA.

## **The Fountain of Youth: Cultural, Scientific and Ethical Perspectives on a Biomedical Goal**

Stephen G Post and Robert H Binstock, Editors  
Oxford UK: Oxford University Press, 2004

ISBN 0-19-517008-3; 463 PP., HARDBACK £42.50

This fascinating volume grew out of a conference on humankind's search for immortality—or at least for prolonged life. The editors of this collection of papers are Stephen G Post, Professor of Bioethics (and Editor-in-chief of *The Encyclopaedia of Bioethics*) and H Binstock, Professor of Ageing, Health and Society and former President of the Gerontological Society of America, both at Case Western Reserve University in America, of which several other contributors are also a part. Like Gaul, the main text is divided into three parts, containing papers on 'The Perennial Quests for Extended and Eternal Life', 'The Science of Prolongevity' and 'Ethical and Social Perspectives on Radical Life Extension' respectively. The titles of the papers are self-explanatory, providing a clear indication of their focus and content.

Thus Part 1 considers: 'The Search for Prolongevity: a Contentious Pursuit'; 'The Quest for Immortality: Visions and Presentiments'; 'Decelerated Ageing: Should I Drink from the Fountain of Youth?'; 'A Jewish Theology of Death and the Afterlife'; and 'In Defence of Immortality'. Part 2 comprises papers on: 'In Search of the Holy Grail of Senescence'; 'The Meta-biology of Life Extension'; 'Extending Human Longevity: a Biological Probability'; 'Eat Less, Eat Better and Live Longer: Does it Work and Is It Worth It?' on the role of diet in ageing and disease; 'Extending Life: Scientific Prospects and Political Obstacles'; and 'An Engineer's Approach to Developing Real Anti-Ageing Medicine'. The six papers of Part 3 cover: 'An Unnatural Process: Why it is not Inherently Wrong to Seek a Cure for Ageing'; 'Longevity, Identity and Moral Character: a Feminist Approach'; 'L'Chaim and its Limits: Why not Immortality?'; 'Anti-Ageing Research and the Limits of Medicine'; 'The Social and Justice Implications of Extending the Human Life Span'; and 'The Prolonged Old, the Long Lived Society and the Politics of Age'.

In addition to the three main parts, there is an 'Epilogue': 'Extended Life, Eternal Life: a Christian Perspective'. I do wonder why there is no response from Islam but assume the Eastern religions are omitted, as major prolongation of life would definitely interfere with the attainment of moksha or nirvana!

Every paper is fully referenced, making this a very welcome academic text—but one which is accessible to the educated layperson. The papers are very 'readable'—but the book takes time as each chapter/paper stimulates much thought and reflection on the positive and negative views expressed on extending the human lifespan. If it is possible to summarise such a volume, I think I would conclude that the consensus is that the problems potentially accruing from extending the lifespan, particularly into immortality, probably outweigh the benefits but that 'decelerating ageing' or 'compressing morbidity' to allow the accumulation of years as current without the accumulation of decrepitude and pathology would be most worthwhile. And that whatever the arguments that can be made against the search for prolonged life, most

writers are agreed that the technology will probably continue to expand whether we like it or not—so we had better spend considerable time and effort thinking about the consequences, if only to ameliorate the worst case scenarios.

An excellent annotated bibliography is provided, covering science, ethics, literature and mythology, history—plus comprehensive notes on primary literary sources on prolongevity, arranged under a number of sub-headings. There are also useful author and subject indices.

As a medical scientist with an holistic approach, who also teaches Ethics and has a long time interest in history, I found this volume a very welcome and rather rare, eclectic, addition to my library. If I have a caveat, it is that the focus is very North American—I admit logically so, given that all but one of the contributors both graduated from and work in universities in the USA. However, the findings of European researchers in the field are given due consideration and frequent mention, so the caveat is minor.

The editors claim that the book addresses a number of highly pertinent questions by 'exploring the ramifications of possible anti-ageing interventions on both individual and collective life . . . it examines the biomedical goal of prolongevity from cultural, scientific, religious and ethical perspectives, offering a sweeping view into the future of ageing'. I think that the claim is fair—and heartily recommend it to all with an interest in the area.

**Gillian M. Kester, Ph.D.**, erstwhile Head of the School of Health Studies,  
University College Chichester, West Sussex, UK.



## Can A Smart Person Believe In God?

Michael Guillen

Nashville: Thomas Nelson Publishers, 2004

ISBN 0-7852-6024-2, 170 PP., HARDBACK, GBP 17.99

Michael Guillen, a theoretical physicist and professing Christian, has been a science correspondent for NBC News, and now serves as Robert Schuller's Crystal Cathedral Ministries' chief consultant for science and religion. In this short book, Guillen counters the popular notion that religion and science are necessarily at odds. The book is written primarily for laypeople, and though the author is extremely knowledgeable and broadly read, he communicates this vast learning in a simple, direct, and easily accessible manner.

Guillen introduces the idea of SQ (spiritual quotient) as the spiritual counterpart to IQ (intelligence quotient), a device that presents his view of the relationship between religion and science in a simple, memorable way. While IQ measures one's intellectual capacities, SQ measures our spiritual intelligence or capacity for awareness of spiritual realities. Though many people value one more highly than the other, Guillen argues that we need both kinds of intelligence in order to have a full, three-dimensional view of reality. He calls those who value and develop only one kind of intelligence Cyclopes. They see from only one eye and thus have a flattened view of reality.

Although addressed to both religious believer and secular skeptic, Guillen focuses primarily on rebutting secular skeptic's arguments. To this end he delineates several varieties of atheism, focusing particularly on what he calls Arrogant Atheists, those who are outspoken and condescending in their unbelief. He responds to several popular anti-religious arguments, explains the difference between science and scientism, shows the limitations, weaknesses, and failures of science, affirms the positive effects of religious faith in historical and personal health terms, and discusses some of the many brilliant people who have expressed their belief in a reality that transcends nature. This last category includes many important contributors to the history of science.

Guillen argues for what he calls a "collaboration model" of the relationship between religion and science where these two ways of knowing complement each other, while existing in their separate domains, neither impinging upon the other's territory. Though he believes human beings need both science and religion in order to have a full picture of reality, he believes that neither science nor religion as such needs the other. Science can never prove or disprove the existence of God, and our faith in him can be alive and healthy without science. Likewise, science can continue to function as an enterprise without ever acknowledging the existence of God. Guillen endorses methodological naturalism (the practice of excluding any reference to supernatural causes from science *a priori*) as a neutral stance, calling it "exclusion without prejudice."(78)

I am uncomfortable with Guillen's acceptance of methodological naturalism, and the way his view puts science and religion into separate watertight compartments. I see this as undermining what the author claims he is trying to do in the rest of the book, which is to grant science and religion equal status as sources of truth about reality.

In our culture, the world that science can study is considered synonymous with the “real world.” Therefore, methodological naturalism effectively bans God from the realm of reality. Religion speaks only to “spiritual” matters, which have nothing to do with the “real world.” Interestingly, Guillen notes that according to the principle of Occam’s Razor (that the simplest explanation is always to be favored), God “is fast becoming the much-sought-after *simplest explanation of all.*”<sup>(77)</sup> But in the same sentence he writes that scientists will never be able to accept this because of the principle of methodological naturalism. This might be a good reason to discard the principle of methodological naturalism.

Allowing God into the realm of science would not need to result in automatically resorting to the extreme of offering supernatural explanations for every phenomenon in nature (i.e. lightening is the thunderbolts of the Gods). God is both immanent in and transcendent of nature, and can work through both natural and supernatural means. Biblical Christianity is fully compatible with the idea that the natural world functions according to its own laws, but understands that these laws are sustained by the immanence of God in nature. If the evidence from science would seem to point in the direction of God, then scientists should be free to consider the possibility that at least some phenomenon in nature exist as the result of His actions. To exclude Him from the start is to bias the interpretation of evidence and automatically favor certain explanations over others.

Despite this major concern with Guillen’s view, I still think that on balance his book provides a good, short, accessible introduction to some of the major issues of science and religion. It effectively and simply counters some of the most popular misconceptions surrounding these issues.

**Gordon Hackman**, Trinity International University, Deerfield, Illinois, USA.





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## BIOTECHNOLOGY UPDATE

NOVEMBER 2005

### Book Review

#### **Radical Evolution: The Promise and Peril of Enhancing Our Minds, Our Bodies - And What It Means to Be Human**

Joel Garreau. New York, NY: Doubleday, 2005.

REVIEW BY AMY MICHELLE DEBAETS

It is appropriate to mention at the outset that this review is being written in New Jersey using the assistance of a laptop computer with a wireless broadband connection to the internet, through which it will be sent by email to a compiler in Chicago and a typesetter in Singapore, each of whom will receive it instantly upon my sending it. The technologies that make all of this possible have been invented within my lifetime and have revolutionized the world in which we all live. The rate of change in technology and the profound human implications of those changes lie at the heart of Joel Garreau's *Radical Evolution*, in which he documents his discussions with prominent techno-futurists such as Ray Kurzweil and Bill Joy and translates those discussions into several possible scenarios that could play out in humanity's near future.

Garreau begins by tracing some of the various converging tracks of the information age and introducing the nonspecialist reader to the "gee-whiz" applications of what he calls the GRIN technologies (genetics, robotics, information, and nanotechnology). In other circles, a similar constellation of fields is known as the NBIC technologies (nanotechnology, biotechnology, information technology, and cognitive science; it would have been helpful if Garreau had included the latter in his discussion). He considers the exponentially-increasing rate of technology processing power, known as Moore's Law, and sees that the curve of this change is beginning to move to a point at which it is nearly vertical. Change is happening so fast that humanity may not be able to keep up with it; we may be reaching a time in which we feel as though we are entering a black hole and must succumb to its overwhelming force - The Singularity. Garreau uses an unhelpfully large number of capital-T "The" terms - The Curve, The Singularity, etc.

The heart of the book are the three scenarios that Garreau puts forth as possibilities for the near-future of humanity: Heaven, Hell, and Prevail. In Heaven, technology is an unstoppable force that leads to the end of war, hunger, disease, and poverty; this view is made popular by Ray Kurzweil and is a compilation of several forms of technoutopianism. The Hell scenario, made known most recently by Bill Joy, is one in which humanity falls prey to any one of the many dangers it creates through technology; it is a technodystopian vision. The final model is not so much a model but an idea that humanity will somehow muddle through the technological changes to come without creating either a perfect world or destroying ourselves and our planet.

The book comes to read something like a classic hero story: given three options, Heaven, Hell, and Prevail, the reader is encouraged to steer between the Scylla and Charybdis of Heaven and Hell to a model of the future in which technology does continue to advance but human beings ultimately triumph, retain their sense of dignity and meaning, and live happily ever due to courage, ingenuity, and luck. It is optimistic about the future of humanity without taking a hopelessly romantic view of technology as the solver of the world's problems. We are not taken over to be made slaves of the machines we create but take control of our own destiny. It is the stuff of summer Hollywood blockbusters: in the face of impending disaster, humanity bands together to save the world for a little while longer.

It is difficult to believe, given this consummately American happy ending, that Garreau truly takes either the promises or the perils of emerging technologies very seriously. The variety and complexity of the technologies he considers warrants a more serious and technical work into the impacts of converging technologies and the likelihood of different scenarios far beyond the simplistic three that are offered in this book, including ones that take a more specific look at the great variety of possibilities that lay somewhere between Heaven and Hell. *Radical Evolution* is an adequate starting point for the newbie reader in emerging technologies to begin to understand what the controversy over the future is about, though it will hold little interest for anyone seeking a more in-depth account of the technologies themselves or serious scenario planning.

## **BIOTECHNOLOGY UPDATE: NEWS AND VIEWS**

BY AMY MICHELLE DEBAETS

### *Patents, Royalties, and Publicly Funded Stem Cell Research*

The debate over the public funding of human embryonic stem cell research typically covers the familiar ground of the moral status of the human embryo and is, in many ways, a rehash of the abortion debate. When the discussion moves on beyond that point, the issues of cloning, genetic engineering, and the slippery slope arise, much of which takes place with the familiar battle lines already drawn, or at least the situation is portrayed that way among the popular media. These issues are real, and the center on the research itself and the question of the scientific imperative: Should science (and, as a corollary, technology) be subject to any restraints? Or should anything that can be done actually be done?

One of the lesser known issues comes directly from the discussion over the public funding of embryonic stem cell research and related technologies, whether on a federal or state level. The question of intellectual property benefits

is finally seeing the light of day in California and New Jersey, where human embryonic stem cell research is publicly funded on a state-wide level. In both of these states, the researchers who receive state grants retain all of the royalties from any patents they obtain based on that research. In other words, a scientist could apply for a grant, receive tax payer money for the research, discover a cure for some dreaded disease using this money, become a billionaire, and not be required to give anything back to the state to fund new research. This raises serious questions about the biotechnology industry's real interest in public funding measures, whether the industry is serious about providing cures for patients or using public money to support potentially lucrative research that venture capitalists would not touch.

California's Proposition 71 was promoted to taxpayers based on the promise that they would receive approximately \$1 billion in royalties in return, though the actuality of this promise is now in serious doubt, as the IRS restricts payments of royalties on certain types of bonds that fund the research. Likewise, it is doubtful that the promise that any therapies found through publicly funded stem cell research would be returned on a free or low-cost basis to Californians who are poor or lack health insurance, as this could violate civil rights legislation. In New Jersey, there is no current provision to return any royalties from publicly funded research back to taxpayers; a bill, S567, has been introduced in two consecutive sessions and has passed the Senate unanimously but failed to pass in the House before the end of the legislative session.

The fact that human embryonic stem cell lines are patentable under United States patent law makes them potentially lucrative for biotechnology researchers and makes the question of the return of royalties in exchange for public funding even more pressing. The question of whether biotechnology companies and the researchers they support have the public interest in mind or whether this type of public funding is merely a cover for corporate welfare. Acting Governor Codey has proposed that 5% of all royalties received from state grants for stem cell research be returned to fund further research, but this is only a proposal and not the way that current funding is being provided. The New Jersey Commission on Science and Technology, the arm of the New Jersey government charged with overseeing the public Stem Cell Institute, has as its mission statement:

To encourage economic development and job growth in New Jersey by:

- promoting strong ties between industry and universities in order to accelerate commercialization of technology
- supporting entrepreneurial technology businesses in areas of strategic importance to the state and
- strengthening research collaborations among universities to create new potential for increased federal funding and private investment.

Nothing in its mission includes working for the public benefit or even medical advance; it is entirely devoted to serving the business sector's interests and is a telling sign of the real rationale behind public funding schemes. The sad irony

is that the biotechnology has most vigorously promoted these efforts among patient advocacy groups, holding out the promise of cures to lure them into supporting public funding of their businesses, only to turn around and demand high prices for their patented services.

In addition to the public funding questions, the issue of patents on embryonic stem cell lines remains, both within the United States and across the world as nations seek to standardize their regulations regarding the patenting of genes and forms of human life; they must be dealt with separately. But perhaps on the question of who benefits from public funding of human embryonic stem cell research, some common ground can be found between those who take differing views of the human embryo. All parties can support patients who are desperate for cures and who need the federal government and the states to make the best decisions for them in funding medical research, not simply throwing dollars at biotechnology companies with no promise of return, but to seek real benefit for those who need it most.

New Jersey S 567, 2004-2005 Session, "Allows NJ Commission on Science and Technology to receive percentage of royalties from certain intellectual property awarded to those science and technology companies assisted by the commission." Available at: [http://www.njleg.state.nj.us/2004/Bills/S1000/567\\_11.PDF](http://www.njleg.state.nj.us/2004/Bills/S1000/567_11.PDF)

Leavenworth, Stuart. "Stem cell royalty promise just an election ruse?," *Sacramento Bee*, November 7, 2005, p. B5.

Tansey, Bernadette. "Tax law casts doubt on stem cell royalties: State may not reap billions promised to voters last fall," *San Francisco Chronicle*, October 25, 2005, p. A1.

Vesely, Rebecca. "Stem cell program may not help taxpayers: IRS doesn't allow royalty payments on tax-exempt bonds," *The Argus*, November 2, 2005.

### *UNESCO Bioethics Declaration*

In October 2005, UNESCO adopted by acclamation a "Universal Declaration on Bioethics and Human Rights," the English version of which is available online at [http://portal.unesco.org/shs/en/file\\_download.php/b0f1e8f1dc4a4e8990faff370608cac2declaration.pdf](http://portal.unesco.org/shs/en/file_download.php/b0f1e8f1dc4a4e8990faff370608cac2declaration.pdf). This eight-page document outlines the major themes in international bioethics and largely reflect the areas of agreement within the field, with a strong emphasis on human rights and patient protection from harm. The Declaration is a landmark of consensus within the global policy community, and it has been hailed by many, religious and human-rights groups. Some who take a more libertarian or utilitarian approach see parts of it as potentially hindering scientific research, as it specifically declares in Article 3: "The interests and welfare of the individual should have priority over the sole interest of science or society," but given the minimalist nature of and overwhelming support for the document, this should not be construed as restricting ethical research conducted in an ethical way; it merely sets out the essential ethical playing field that comes directly from the tradition of the Nuremberg code.

The priority placed upon human rights within the context of global pluralism and diversity is a strong model by which global bioethics discussions may be approached. Nothing in the document is particularly unusual or out



of left field, but the fact that it was adopted without dissent speaks to at least some progress toward consensus on the basic position that bioethicists, health care workers, and biotech researchers should take with regard to their patients' needs and the larger societal need. For instance, Article 8 focuses on respect for human vulnerability when dealing with the seemingly endless march of medical technology. Article 12 places the importance of pluralism in an important place, but this does not give rise to a situation in which 'anything goes.' Rather, pluralism is fully acceptable within the bounds of basic human rights; they "are not to be invoked to infringe upon human dignity, human rights and fundamental freedoms, nor upon the principles set out in this Declaration, nor to limit their scope."

The UNESCO document draws primarily upon the approach of ethical principles, most famously laid out by Beauchamp and Childress in their classic text, *Principles of Biomedical Ethics*, for many years now the standard text in secular academic bioethics. It goes beyond the four basic principles of beneficence, nonmaleficence, autonomy, and justice, though, including articulating the need to assess and take into account "the impact of the life sciences on future generations, including their genetic constitution" (Article 16). The environmental impact of modern medicine and biotechnology is likewise given consideration not often found in traditional (Western) bioethics literature. It includes the need for transnational cooperation to eliminate trafficking in human organs, tissues, and genetic information and for bioethical education at all levels, particularly the moral development of young people in a rapidly changing technological world.

The Declaration also places emphasis on social responsibility; the health and welfare of all people should be promoted without discrimination based on "race, religion, political belief, (or) economic or social condition" (Article 14). This declaration that "The promotion of health and social development for their people is a central purpose of governments, that all sectors of society share." (Article 14). If the declaration is taken seriously, this may help mitigate the effects of a purely market-based healthcare and health insurance system, while not placing the entire burden of healthcare upon the government. It outlines the minimal needs of the people for which the society as a whole bears a burden, including "access to quality health care and essential medicines...access to adequate nutrition and water; improvement of living conditions and the environment; elimination of the marginalization and exclusion of persons on the basis of any grounds; and reduction of poverty and illiteracy" (Article 14).

While the UNESCO Declaration has a broad scope and no direct force of law, it is an important document in the global community, as it raises the pressure for nations to take its principles seriously in making ethical policy decisions. It follows two other important Declarations, one on the Human Genome and Human Rights (1997) and the other on Human Genetic Data (2003). The Declaration has received little press in the West, and in the US particularly, but its impact long term and on developing nations may be significant.

For more information, go to:<http://www.un.org/apps/news/story.asp?NewsID=16296&Cr=UNESCO&Cr1=Bioethics>





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