Reframing autonomy in informed consent

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ABSTRACT

Medical informed consent has been governed by the principle of autonomy. How autonomy is conceived and codified has led to current understanding and behavior expectations in healthcare decisionmaking. It has become obvious that the consequences for those who do not share the dominant view are potentially problematic.

This thesis begins with a consideration of some of the ethical problems encountered within the current framework of informed consent. It traces the historical development of informed consent as a philosophical and legal concept with multidimensional influences. An analysis of the autonomy paradigm based in a concept of liberal individualism is presented. This is then contrasted with a relationship-centered care perspective as an alternate moral framework for healthcare decisionmaking. Finally, a redefined notion of autonomy and reconception of roles and relationships that considers a relational normative framework within informed consent is proposed as a more inclusive, individual focused model for healthcare decisionmaking.
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INTRODUCTION

The concept of informed consent at first seems to be so widely accepted that it hardly seems worth discussion any more. Anyone entering the healthcare system will quickly be asked to consent to something, large or small. A person cannot have a procedure done as inpatient or outpatient without being handed or verbally given a long list of potential risks of the prospective procedure, and is always asked to sign some kind of consent form. This is the current state of the art of informed consent. It has been the case since the emergence of legalized, detailed consent forms in the late 1960s. It all seems so mundane.

At the same time, the concept of informed consent is the heart of contemporary bioethics. But as one delves deeper into the field, especially in clinical bioethics, the contrast between what is intended by the popular notions versus the formal or legalistic notions of informed consent becomes obvious. This contrast is the reason for this thesis.

The predominant approach in bioethics theory to the issue of informed consent as an expression of self-determination has been that of trying to define those elements of autonomy that are required in order to satisfy a condition of informed consent. This approach stems from a concern that those who are capable of autonomous decisionmaking should be enabled to do so, and those who do not have the capacity should be protected from potentially harmful or unwanted bodily invasion by those in medicine and research. It also stems from strong legalistic concerns that favor proof of
informed consent and therefore require satisfaction of certain elements in that proof. An even stronger bias is the assumption that all or nearly all persons want to make their own decisions and that if those decisions are to be considered rational, they must include all relevant information available for consideration. The first two concerns, that of enabling autonomous persons to make their own decisions and protection for nonautonomous persons, are concerns regarding the well-being and autonomous expressions of individuals concerning their bodies, healthcare, and sometimes death. The legal concerns have more to do with satisfying a need for a false sense of security from liability in the practice and provision of medicine and healthcare. The concern regarding rationality of decisionmaking stems from a particular view of the self, others, and the way persons go about making decisions. However, it seems in retrospect that what was unwittingly accomplished by these concerns and under these assumptions was to promote a particularly narrow perspective of what personal autonomy means, and to place even greater distance between patients and professionals in considerations of the patient's best interests.

In my experience as a clinical ethicist at the bedside of patients, most in critical and/or terminal conditions, the traditional application of bioethics principles to the complex and personal issues of individual patients and their families and loved ones was both frustrating and inadequate. This approach to moral reasoning seemed cold, impersonal and wholly detached from the reality of the situation. Considering the expressed or assumed interests of the patient as the primary and ultimate value likewise seemed inadequate, leaving the patient's intimate others in a role of little importance or
consequence in facing the circumstances of the patient's death. This experience led very quickly to reconsidering the approach called "principlism" as appropriate for universal application in such situations. Something very intimate and immediate was missing. It did not fit the situation. All too often I found myself resorting to other methods, primarily that known as narrative process ethics, in approaching decisionmaking with families of patients. It seemed more morally appropriate than the predominant approach because of its responsiveness and consideration of particulars and it led to a morally acceptable outcome for those involved.

Another area of difficulty was with the predominant conception of autonomy as the property of a self-interested, self-directed, self-actualized independent person capable of fully articulating one's own values as they pertain to a medical situation. The judgment of another's rationality in decisionmaking based on such a view of the self did not mesh with my intuitions concerning the decisionmaking of the patients and families I encountered. For example, many levels of influence play a role in the decisionmaking process and it seems appropriate that sometimes they should. Sometimes it is appropriate to attempt to persuade a patient to a particular course of treatment especially when the benefits are high and certain and the risks are low and unlikely. However, this is not to say that the only time influence is justifiable is when it promotes the view of medicine. Other views may help a patient clarify previously unknown or underdeveloped values in a new situation, or reconsider previously steadfast ones that no longer seem appropriate. Yet other views are routinely dismissed, ignored or viewed as coercive by healthcare professionals if they differ from the medical view. Similarly, persons who do not fit the
profile of autonomy as defined, or who as surrogates do not blindly follow the expressed wishes of the patient, are judged by professionals as unfit for decisionmaking. As the numbers of individuals who fall into this category grew, it seemed to me that the definition of autonomy for decisionmaking is too narrow to accommodate the realities of persons and what counts as appropriate for autonomous decisions. My intuitions about persons and where the boundaries between autonomous and non-autonomous decisions fell were outside the current boundaries drawn in most bioethics theory. The questions that surfaced included, what really is autonomy? Could it be that all these individuals who do not meet this definition or accept it are not autonomous? Or is it the definition itself that is the problem?

The problem of articulating a justifiable moral account of autonomy in informed consent is the root of this thesis. The predominant approach in bioethics theory has been one from the individualist, rationalist tradition of moral reasoning. That tradition sets moral problems in the framework of competing moral interests of rational individuals. I argue in this thesis that although that tradition was important as the first wave of articulation of values in the appropriate use of medicine and the self-determination of patients, it is inadequate for a number of reasons. I argue that the art of healing, which considers the individual as inseparable from the complex of relationships with others and one's life experience, must be taught to healthcare professionals as thoroughly as the science. I argue for a reframing of the concept of autonomy in the context of healthcare decisionmaking to one which encompasses a larger, more diverse expression of self-determination and which refocuses the roles of families and professionals in that process.
CHAPTER 1

PROBLEMS WITH HEALTHCARE DECISIONMAKING AND INFORMED CONSENT IN AN AUTONOMY PARADigm

To a large extent, current thinking regarding healthcare decisionmaking and medical informed consent has emerged as a result of post-World War II global reactions to Nazi medical experimentation on concentration camp prisoners and later, the refutation of medical paternalism common in nearly all medical decisionmaking of the past. It has been suggested that these two primary influences eventually culminated in the development of current bioethical thinking concerning the theoretical imperatives of patient participation, autonomy as self-determination, and informed consent. This has, in turn, led to the development in U. S. bioethics of what is usually considered necessary for a condition of informed consent. It is generally agreed that, "proper consent requires decisionmaking capacity; adequate information about risks, benefits and alternatives; details about the nature of the [proposed] procedure; understanding; and freedom to refuse the [proposed] procedure." These requirements concerning information and capacities for informed consent are based on what is generally understood in contemporary U. S. bioethics to define patient autonomy or autonomous decisionmaking in healthcare. Over the past twenty to thirty years, this understanding has become nearly universal in U. S. bioethics theory and, in most situations is still expected in practices.

5
concerning informed consent.

The theoretical development of healthcare decisionmaking and informed consent is grounded in a moral assumption of the duty of respect for the autonomy of others. This moral grounding is consistent with the ideals of political liberalism on which this country was founded. However, it has recently become evident that the expectation, indeed the requirement in law, of its application in virtually all but emergency medical situations has led to many previously unrecognized problems.

One of the purposes of informed consent is to provide persons with information concerning a proposed procedure or therapy in order to enhance healthcare decisionmaking of autonomous persons. This information includes such specifics as the diagnosis, explanation of the clinician's preferred treatment plan together with potential risks and benefits, alternative options with risks and benefits, and likely outcomes of each. It has been assumed by those who initially formulated this concept and many who followed that this type of information would assist the autonomous person in making a decision that would be consistent with fulfillment of the vision of a good life. This assumption is based in the value and importance of individual autonomy and the value and importance of fully informed consent in enhancing individual autonomy. However, it is also possible that these assumptions may represent a misinformed expectation of universal acceptance of this moral grounding by those who comprise American society. Reflection on the pluralistic nature of our society as well as growing experience using these assumptions in clinical situations has raised to light some problems inherent in their universal application.
This chapter will focus on explicating some of these problems within this paradigm of an autonomy-based theory of healthcare decisionmaking and informed consent. These problems have surfaced over the past several years in various clinical situations within cross-cultural settings and with families, especially spouses, facing surrogate responsibilities in decisionmaking. Two of the examples used here come from personal professional experience. The other two have been published in bioethical and medical literature.

**Cultural Perspectives**

**Traditional Navajo Perspectives**

In late 1995 Carrese and Rhodes released the results of recently completed research concerning the perspectives of Native Americans from a traditional Navajo tribe in Arizona concerning information generally required for medical informed consent. The study was intended to assess the efficacy of the current Western medical practices of information and truth-telling in informed consent. Specifically, they focused on the practices of discussing outcomes of diagnoses and proposed treatments, including potentially adverse outcomes, with these Navajos for the purposes of informed consent and Advance Directives. It is noteworthy that prior to this study very little research has been done concerning various ethnic communities' cultural values and moral perspectives concerning common medical practices in the United States in comparison to the dominant societal, medical and bioethical views. What few studies had been done suggested that there are significant differences among various cultural communities that should be
understood and appreciated within the study of bioethics and medical practice.\footnote{1}

Carrese, the principal clinical researcher in this study, had been practicing medicine on a Navajo reservation in Arizona for 4 years. He had anecdotally noticed that certain Western medical and bioethical concepts and practices seemed to regularly conflict with traditional Navajo values and ways of thinking.

One of these areas of conflict revolves around the practice of discussing "negative information," such as disclosure of risks, "bad news," such as adverse outcomes, and advance care planning for critical events, such as Advance Directives. Current standards of practice, based on the principles of respect for a person's autonomy and self-determination, require direct and explicit discussion of this type of information between healthcare provider and the patient. For example, the principles of informed consent require truthful disclosure of potential risks and outcomes of diagnoses and proposed medical treatments. Truth telling itself requires disclosure of a likely fatal outcome; and advance medical care planning requires the discussion and consideration of a serious, potentially fatal illness in the future. The extent to which these practices are accepted and expected within the standards of Western medicine is evident in the fact that physicians have successfully been held liable for failure to meet these standards.\footnote{5}

However, traditional Navajo culture holds that language and thought do not merely describe reality; they have the power to shape reality. For this reason, many traditional Navajos view the discussion of "negative information" as potentially harmful to their well-being. A central concept in their worldview is harmony with Nature, being in balance with all that is in the universe. Navajo healing is not directed toward the
symptom but toward bringing the whole person into harmony through the use of symbols and prayers. This harmony, therefore, must be restored in body, spirit and mind.\(^5\)

In his study, Carrese interviewed thirty-four Navajos, 16 men and 18 women, six of whom functioned as traditional healers, and seventeen of whom spoke only Navajo. Two dominant themes emerged from the interviews and analysis of the data. First, the participants often commented on the importance "to think and speak in a positive way." The Navajo expression of this concept can be translated as "think in the Beauty way" and "talk in the Beauty way," which reflect the Navajo view that thought and language have the power to shape and control both reality and events.\(^7\) It is expressive of the Navajo view that health is maintained or restored through positive ritual language.

Another side to this concept is that healthcare providers should avoid thinking or speaking in a negative way. Such thoughts and language by healthcare professionals distressed many traditional Navajos since their view is that negative thoughts and words can result in direct harm. What is considered routine discussions for informed consent for surgery, for example, including the remote risk of death, can so severely affect a traditional Navajo patient that she may refuse the surgery as if a death sentence, no matter how physically necessary the surgery is from a medical perspective and how statistically remote the potential risks.\(^8\)

The second revealing theme of the study involves the Navajo perspective concerning advance medical care planning through Advance Directives. One of the primary goals of the Patient Self-Determination Act (PSDA) of 1991 was to increase patient participation in their own end-of-life decisionmaking by encouraging adults to consider and reflect on
the possibility of a profoundly debilitating, life-threatening illness in the future.9 To this end, the Act requires that all adults admitted to hospitals and other facilities be provided with written material concerning state laws and facility policies regarding the patient's right to formulate advance directives. In addition, it requires that education be provided to staff and the community about issues concerning advance directives. In 1992, the Indian Health Service adopted the requirements of the PSDA and stated that, "Tribal customs and traditional beliefs that relate to death and dying will be respected to the extent possible when providing information to patients on these issues."10 Carrese reported that 86% of the Navajo participants in his study stated in one way or another that this practice was "a dangerous violation of traditional Navajo values and ways of thinking." Only three of the twenty two respondents (14%) found this practice acceptable, and they were Navajos trained in Western medical healthcare and employed by the Indian Health Service.11

Although the participants in this study do not reflect the views of some Navajos more aculturated to mainstream U. S. society, their views do seem widely held within the Navajo culture as a whole.12 It has also been pointed out that there is a great amount of homogeneity within the Native American nations concerning many traditional views as expressed by these Navajos.13 Thus the requirements of the PSDA for universal application to all admitted patients and the education of staff and members of the community are, the authors point out, ethically troublesome. With respect to the traditional Navajo community, advance care planning and informed consent discussions may well be viewed as potentially harmful to the individual who holds traditional Navajo
views.

Such findings suggest that there needs to be much reflection and perhaps remodeling of the requirements of both federal law and Indian Health Services policy due to the potentially profound adverse effects on the well being of Native American peoples. In addition, these findings further suggest that the prevailing Western medical concepts and practices, and the prevailing principles of U. S. bioethics, are not universally held or accepted even within the boundaries of this country. The pluralistic society that comprises the whole has within it communities of people who do not identify with the dominant values.

Korean-American and Mexican-American Perspectives

At the same time as the Carrese research publication in 1995, Blackhall, et al., published their findings of a survey of four ethnic groups concerning disclosure of diagnosis and prognosis of terminal illness and end-of-life decisionmaking. The survey sample of 800 subjects, sixty five years and older with equal numbers of men and women, were individuals from one of the following ethnic groups: Korean-American, Mexican-American, African-American or European-American.

This study differed somewhat from the Carrese study in that it focused on the prevailing moral principle of respect for and importance of individual autonomy and self-determination as the basis of current informed consent practices. This principle asserts the right of individuals to make healthcare decisions for themselves based on relevant information. Thus, the importance of truth telling is integral for those charged with the
duty of respect for others' autonomy. As previously noted, truthtelling is generally understood in this context to include the truth regarding the person's diagnosis, risks and benefits of proposed treatments, and options to the proposed treatment with risks and benefits. This kind of truth is also generally understood to include information about fatal illnesses and discussions and planning regarding end-of-life medical options. As the authors point out, however,

This focus on patient autonomy has become overly narrow and...other values, such as family integrity...have been ignored. In particular, some have argued that this preoccupation with individual rights to the exclusion of other values may reflect a cultural bias on the part of the Western medical and bioethics communities.15

This study focused on attitudes toward autonomy in relation to ethnicity, age, religion, level of education, and income. Other factors were also included, such as functional status, acculturation, access to healthcare, and experience with illness and with treatment limitation issues, including withholding and withdrawing life-support.

Interviews were conducted by trained persons whose ethnic backgrounds matched those of the four groups in the study, and who were bilingual if Korean-American or Mexican-American.

The outcome of the study is as revealing as the Carrese study. Korean-Americans (47%) and Mexican-Americans (65%) were significantly less likely than European-Americans (87%) and African-Americans (88%) to believe that a person should be told the truth regarding the specific diagnosis of metastatic cancer. Likewise, Korean-Americans and Mexican-Americans were significantly less likely than either African-Americans or European-Americans to believe that a person should be told of any terminal
prognosis, or that the person should be asked to make decisions regarding the use of life-support. Both Korean-Americans and Mexican-Americans (57% and 45%, respectively) also believed that the family should make these decisions. Regardless of the differences in groups regarding truthtelling to the patient, 90% of all the participants in all groups believed that the family should be told the truth about the diagnosis and prognosis. "The difference is that the Korean-Americans and Mexican-Americans were more likely to believe that only the family and not the patient should be told the truth."16

Of further interest in this study is that the degree of acculturation of Mexican-Americans had a direct correlation as to whether they agreed that the patient should be told the truth about their diagnosis and prognosis. Those with a higher degree of acculturation were more likely to agree. Those with less acculturation (79% of the Mexican-American group) were less likely to agree. However, acculturation itself had no significant effect on the choice of the patient as primary decisionmaker, with the majority believing that the family should make the decisions, as noted above. Interestingly, 100% of the Korean-American participants scored so little in acculturation factors that they could not be included in this part of the study. The degree of acculturation was not related to the length of time living in the United States, for both Korean-Americans and Mexican-Americans. For Mexican-Americans acculturation was, however, directly related to either income (greater than $10,000 per year) or years of education (6 years or more) or both.

For Korean-Americans and Mexican-Americans, agreement with truthtelling and patient as primary decisionmaker were related to higher levels of education,
socioeconomic status and age, in that older, lower income and less educated participants were less likely to agree. For European and African-Americans, however, socioeconomic status alone did not predict attitudes toward patient autonomy and decisionmaking. It seems, then, that factors of socioeconomic status are more directly related to acculturation, and the degree of acculturation is then related to attitudes regarding patient information, autonomy, truth-telling and decisionmaking.

The authors suggest that the decisionmaking style of both Korean-Americans and Mexican-Americans can be described as family-centered. In both groups, it is the responsibility of the family, rather than the patient, to bear the burden of bad news and subsequent decisionmaking. This is seen in other ethnic groups as well, such as in Italy, Greece and Japan, and in Chinese and Ethiopian immigrants. In these groups, autonomy and truth-telling is viewed not as empowering, but rather as isolating and burdensome to those who are sick.

Blackhall, et al., conclude that the ideal of patient autonomy and self-determination is far from universal. The high value placed on open discussion, information and the right of the patient to choose for oneself in Western medical and bioethical models are likewise not shared by all members of U. S. society. As they suggest, persons live, get sick and die within the context of their family and culture, embedded in the woven fabric of relationships, rather than as solitary individuals. "For those who hold the family-centered model, a higher value may be placed on the harmonious functioning of the family than on the autonomy of its individual members." The insistence on the autonomy model by the medical and bioethics communities may be perceived as a violation, or harm, of cultural
values and conventions when they insist on telling the patient the truth. Thus, forcing an autonomy model of medical decisionmaking when that model is contrary to the family-centered values of some patients and their families may well be just another form of medical paternalism, in essence a reconstructed, new and yet not new meaning of the old phrase, the doctor knows best.

Substituted Judgment, Best Interests, and the Family: Two Cases

When persons under medical treatment do not have the capacity to make decisions concerning their healthcare options, including the options of life-sustaining treatments, the prevailing view in prominent bioethics literature and tort law is that incapacitated persons have the same rights (autonomy, self-determination and privacy) as persons who have decisional capacity. However, for those who do not have decisional capacity a surrogate decisionmaker is appointed to exercise this right on their behalf. Most often in healthcare settings, if the patient did not previously appoint someone to act as their surrogate a family member or close friend is appointed informally, that is, not through the court. Some states, including Nevada, provide a delineated hierarchy of family members for the order in which a surrogate may be informally appointed.

It is generally accepted in current U. S. bioethics that there are two substantive standards for guiding surrogates in decisionmaking. Although neither of these standards has a clear grounding in respect for autonomy, nonetheless appeals to autonomy rights are frequently used in defense of their use by both bioethicists in theory and defense lawyers in court.
One standard is that of best interests. Under this standard, a surrogate makes decisions regarding healthcare treatments for what is believed to be the highest benefit to the patient based on a comparative assessment of benefits and burdens of the various options, including life-sustaining treatments. As usually understood in the bioethics and legal literature, "The best interests standard protects another's well-being by assessing risks and benefits of various treatments and alternatives to treatment including consideration of pain and suffering, and by evaluating [the likelihood of] restoration or loss of functioning. It is therefore inescapably a quality of life criterion."^{23}

Respect for autonomy is a consideration within this standard insofar as various autonomous preferences of the person may be known, and, thus, may affect interpretations of quality of life considerations.^{24} Such is usually not the case, however. This standard is usually considered most appropriate for persons who never had decisional capacity and whose preferences regarding the proposed treatment cannot be known. Quality of life considerations are generally understood in this context to entail not the socioeconomic worth of the individual, but rather, the value of this life under these circumstances for the one who must live it. As understood, however, it may also seem to inadvertently allow other considerations and biases to creep into the equation in the decisionmaking process of the surrogate, albeit unintentionally, which are not necessarily in the best interests of the patient.

The other standard is that of substituted judgment. This standard is usually understood within a medical context to entail decisionmaking by a surrogate based on previous knowledge as to whether the person would have consented or refused such
proposed treatments in the specific, or sufficiently similar, circumstances at hand. In this understanding of substituted judgment, protection of the rights of autonomy, self-determination and privacy are the primary intent.\textsuperscript{25} It is, in general, perhaps most appropriately applied in cases of patients who once did but no longer have decisional capacity.

The well-known case of Karen Ann Quinlan in 1975 was the first to actually refer to this standard for surrogate decisions in a healthcare, life-sustaining treatment context.\textsuperscript{36} In this case, substituted judgment was understood as requiring direct knowledge of the patient's previously expressed autonomous preferences regarding the proposed treatment under the specific, or very similar, circumstances. Thus defined, it may be understood as a primarily subjective interpretation of the standard.

More recently, however, substituted judgment is widely accepted both in courts and in bioethics theory as a process whereby the surrogate substitutes her judgment regarding proposed treatment for what may be the specifically unknown, yet substantially arguable, presumed wishes of the person who does not have decisional capacity. Such an understanding was first applied in the Saikewitz case.\textsuperscript{27} This differential understanding has been viewed in the literature on bioethical theory and law as an objectification of the subjective standard. In this understanding, a surrogate may consider a variety of factors from which the patient's subjective intent can be inferred. Such factors may include, but are not limited to, what most others would likely want under the same circumstances, the patient's age, probable side effects of treatment, chances of cure and whether temporary or permanent, the likelihood of additional suffering caused by the treatment, and the
patient's ability to cooperate with the treatment, so as to avoid physical restraints and thus cause further pain, suffering and fear.28

These two standards, best interests and substituted judgment, are the primary sources of guidance given to surrogates for making decisions regarding healthcare options for another person. They can provide some of the guidance needed for some surrogates in some circumstances. This is especially the case in situations in which the surrogate is unsure about what to decide because of uncertainties concerning previously stated preferences of the now incapacitated person (substituted judgment), or completely unknown and never expressed preferences (best interests). However, problems can and do arise within the limitations of these standards particularly in situations involving surrogates, usually close family members and especially spouses, who may know the patient's wishes but for a variety of reasons are unable to effect those wishes. These problems may be traceable to the autonomy-based model of decisionmaking from which they have emerged, and which they are largely intended to support. In addition, the broad acceptance of these two standards for surrogate decisionmaking by theorists, the courts and healthcare professionals as appropriate basis for such deliberations may have created an atmosphere in which the expectation is that surrogates adhere to these two standards exclusively. When a surrogate does not, the judgmental reaction toward the surrogate by healthcare professionals involved in the patient's care may result in added distress for the surrogate at the least. At the worst, it may at times result in outright hostility toward the surrogate, depending on the degree of discomfort for these professionals caused by what is perceived as a threat or disregard of the patient's autonomy rights. The following two
 Case #1: Mrs. B

The patient, Mr. B, was an eighty-five year old patient in the Intensive Care Unit (ICU). He had been admitted three weeks prior with known cancer of the prostate which had metastasized to the liver, chronic obstructive pulmonary disease, and chronic coronary artery disease. Very shortly after admission, Mr. B went into shock followed by a respiratory arrest that led to his admission to the ICU. Since that event, he remained on the ventilator and subsequently developed what is known as multiple organ system failure or total body failure, including adult respiratory distress syndrome, renal failure requiring daily dialysis, sepsis and deep vein thrombosis. In addition, a new retroperitoneal mass had been found and was assumed to be additional metastasis from the prostate cancer. All indications, as noted by virtually all of the medical specialists, were that the expectation of survival for Mr. B under these circumstances was essentially nil. It was agreed by all professional staff that Mr. B's life would end soon, and that removal of all life-sustaining treatments to allow for a natural death process with maximal comfort measures would be the most that medicine could offer him.

Mr. B had been responsive and seemed to comprehend what was said to him. He had recently indicated to his long time physician that he was tired and was ready to die. When the physician approached Mrs. B, the patient's wife of sixty-eight years who was eighty years old herself, regarding withdrawal of life-sustaining treatments, Mrs. B refused to agree. Two days later, Mr. B was no longer responsive. Since there was no
advance directive, the situation required the wife to sign a written consent of agreement
to withdrawal of treatment. Despite numerous attempts by the physician and other
healthcare professionals she remained steadfast in her refusal to agree on the grounds that
she would not permit anyone to cause her beloved husband to die. She sat vigil every day
and into the nights holding his hand in hers. There was no other family to turn to for
support or input for her, or as a resource for the staff. The attending physician felt that on
one hand she was betraying Mr. B's autonomously expressed willingness to withdraw
life-sustaining treatments, and that he was ready to die. Yet, on the other, she felt
responsibility to Mrs. B who also was her patient. Mrs B would have to live with the loss
of her husband and the psychological effects of a refusal to honor her decisions. The
professional staff caring for Mr. B were expressing in verbal and nonverbal language
their growing distrust of Mrs. B. They suggested that either she was too senile to
participate in the consent on behalf of her husband or she had ulterior motives such as
pension or social security income that were influencing her refusal to "let the poor man
die." It was also suggested by some professional staff that perhaps the hospital should
consider legal action against her for not respecting his autonomy rights, not acting in
good faith according to the expressed wishes of her husband, and that as a result she was
causing him harm.

When one took time to sit with Mrs. B, to talk with her and listen to her story about
why she refused to consent, however, a different understanding of her motivations
emerged. She was well aware of how critically ill her husband was, of their physician's
the conversation with her husband, and of the fact that her husband would likely die with
or without the life-sustaining treatments because it was more a matter of when not if he
would die. She knew that in order to remove the life-sustaining treatments her signature
was required in giving consent. She was also well aware that virtually all of the
professional staff she encountered wanted and expected her to sign the consent, and that
her refusal to do so was causing "some unpleasantness" by them.

When asked about her understanding of her husband's pain and suffering as a result of
the invasive nature of the treatments he required, she replied that she did not think that he
was in pain. He did not look like he was in pain. Indeed, he hardly moved a muscle, so
how do they know he is in pain? And besides, she was there to smooth his brow, wipe
his face, hold his hand. When asked about her husband's indications that he was tired and
ready to die, she replied that she did not feel that meant he was ready to leave her right
away, right now, today. Rather, they knew that some day they would both die, but if
they could forestall it for as long as possible they could spend as much time together as
possible. She said that she did not believe that he really wanted to leave her. So, as long
as she could still hold his hand, as long as there was still warmth in him, then he still was
with her and she with him. She believed that he knew she was there, even if he could not
show it. These were her reasons for not consenting.

**Case #2: Mrs. M**

Mr. M was an eighty-nine year old man admitted to the hospital known to have end-
stage cancer of the lung with metastasis to the bone, also suffering progressive weakness,
decreasing mental status and increasing lethargy. He did not have an advance directive,
and refused to enact one on admission. Two weeks after admission, Mr. M was clearly deteriorating. Since there were no medical interventions that would significantly enhance his condition and there was no cure for his illness, the primary physician and medical specialists agreed that, due to his overall condition, Mr. M would not benefit from any aggressive medical interventions and should be supported with maximal comfort measures for however long he would survive. Mr. M was no longer capable of participating in his own healthcare decisionmaking.

The primary physician discussed at length with Mrs. M the details of the situation, including Mr. M's terminal prognosis and his unlikely survival of aggressive interventions such as cardiopulmonary resuscitation (CPR) when his condition deteriorated further, as inevitably it would. Although viably distraught, Mrs. M agreed that such interventions would only prolong his dying, and she believed that her husband would not wish to do that. She also stated that her husband would prefer to die at home, and she wanted to do that for him. Mr. M's physician wrote orders for treatment limitations accordingly, and started arrangements to help Mrs. M take her husband home to die.

On the day Mr. M was to be discharged home with hospice home care, Mrs. M suddenly told the staff that she had changed her mind and that she would not be taking her husband home. Furthermore, she wanted the orders changed so that her husband would receive all treatments available to keep him alive, regardless of the outcome. Later that day the physician received a phone call from Mr. M's sons in Massachusetts telling him that they wanted everything done to keep their father alive. When he explained that
interventions such as CPR would be futile for their father because he would die with or without them, they said they still wanted everything possible done. The physician was concerned over the prospect of being sued by the sons if he did not go along with the family’s wishes, especially since Mrs. M was now expressing the same wishes as the sons. The professional staff was visibly frustrated by Mrs. M’s refusal to remain with her original decision despite numerous attempts to “reason with her.” They felt that she was in a panic over the prospect of her husband’s impending death, and that she was going against her husband’s wishes as she had expressed them so clearly just a few days ago. Once again, they saw this as a direct betrayal of her husband since the legal responsibility for the consent or refusal was hers. Furthermore, they expressed concern that perhaps she now had other ulterior motives, such as social security income, for changing her mind so suddenly.

As in the first case, when one sat with Mrs. M to talk with her and listen to her story, a different understanding again emerged. Both Mr. and Mrs. M were Filipino, born and raised in the Philippines, who had come to this country many years ago to make a better life with more opportunities for their sons. Although they had, in their estimation, become quite Americanized, and their sons had benefited from an American education and now successful jobs, they still adhered to some of the deep-seated traditions of their culture. One of these traditions is that the Filipino culture, like many Asian cultures, is strongly paternalistic. When the head of the household, always the husband/father, is no longer capable of such responsibilities due either to mental infirmity or other ailment or death, the eldest son automatically takes over all responsibility for family matters. The
wife/mother has, in essence, no voice in family decisions, even if she personally disagrees
with decisions made by the son. If the wife/mother should outwardly disagree with the
son's decisions, especially if she takes action that is contrary to such decisions, the
consequences for her are usually quite severe. In her case, Mrs. M would be ostracized
from her family, never allowed to see her grandchildren, cut off and left to fend for
herself. Mrs. M viewed this kind of reprisal as too much to bear after losing her husband.
In Filipino culture, family plays a central and essential role in the lives of both women
and men, although in different ways. This is especially true for elderly parents who are
provided for by their adult children. Mrs M felt compelled to honor her son's wishes,
even though she and her husband would have preferred for him to die at home.

As these two cases illustrate, the autonomy model of decisionmaking has a pervasive
hold on the understanding, expectations and attitudes of healthcare professionals
regarding the role of surrogates and their decisionmaking process. It is so much so that
when a surrogate does not conform to expectations of enactment of the patient's
autonomy rights, especially when the substituted judgment standard seems most
appropriate, reactions of the staff can at times contribute in subtle and not so subtle ways
to the grief and suffering of the surrogate, oftentimes an elderly female spouse.
Furthermore, under current law, any surrogate may be removed from their role in critical
decisionmaking if their decisions are perceived to be contrary to the patient's
autonomously expressed wishes. This type of legislation further promotes and sustains
the prevailing view about the primacy of autonomy rights. Ultimately, it leaves little
room for serious consideration of other, possibly equally legitimate concerns in the
personal lives of patients and their families for whom individual autonomy does not overshadow the concerns of others.

**Conclusions**

This chapter has focused on presenting a brief overview of some of the most widely held tenets of current bioethical theory and law regarding healthcare decisionmaking, informed consent, and the role of surrogates in this process. In the first half of the chapter, the primacy of an individual's autonomy rights was reviewed as the basis for healthcare decisionmaking and informed consent. However, as demonstrated in the first two examples, individual autonomy, as understood and reinforced in policy and law regarding informed consent, is not as universally held as one might expect given this country's political foundations in liberal individualism and personal freedoms. In our collective diversity, many different cultures and ethnic groups remain active and centrally situated in the lives of many in our society. Many worldviews and ways of decisionmaking are based on values considering the nature of relationships that place things other than the individual at the center of considerations concerning life and death. They could be viewed, perhaps, as more symbiotic relationships than ones of independence, self-sufficiency and self-determination.

The second half of the chapter considered the role of the surrogate in informed consent for healthcare decisionmaking based on two widely held standards, best interests and substituted judgment, both of which are also grounded in respect for individual autonomy. The two cases demonstrated the kinds of problems that have begun to surface
in specific situations involving surrogates who do not seem to conform to the expectation, viewed by some as a legal mandate, to make decisions based on autonomous expressions of the patient's wishes. This is especially true in situations where the surrogate is expected to make decisions based on an autonomously expressed intent by the patient with regard to current circumstances (substituted judgment standard). The expectations of healthcare professionals regarding the behavior of surrogates is at least in part due to a pervasive, possibly rigid, paradigm of the autonomy model. Within this paradigm, it seems that little room is left for other considerations of importance as viewed by those most intimately in relationship with the patient.

This criticism of the autonomy model it is not intended to completely denigrate all notions of respect for the autonomy of others. Rather, it is an attempt to step back out of the paradigm, to look more critically at it and its effects, and determine if anything more constructive may in part help to alleviate these problems we are now experiencing in its wake. To this end, the next chapter will specifically consider the development of current thinking regarding healthcare decisionmaking, particularly the development of informed consent for decisionmaking, from a philosophical and legal historic view.
NOTES


2. Dagi, 248.


7. McCabe.

8. Id.


16. Blackhall, 822. All statistics in the next two paragraphs are from Blackhall.


19. Alan Meisel, *The Right to Die*, (NY: Wiley Law Publications, Wiley and Sons, 1989), 46-47, and 55-56; A discussion of the determinants of decisional capacity will be found in chapter 3 of this thesis. For a brief overview, see Meisel, 191-201.

20. Ibid., 181-183, and 223-234, including footnotes.

21. NRS 449.626 states: 2) The authority to consent or to withhold consent under subsection 1 may be exercised by the following persons, in order of priority: a) the spouse of the patient; b) an adult child of the patient, or, if there is more than one adult child, a majority of the adult children who are reasonably available for consultation; c) the parents of the patient; d) an adult sibling of the patient or, if there is more than one adult sibling, a majority of the adult siblings who are reasonably available for consultation."


24. Ibid., 178-181.

25. Ibid., 171-173.

26. *In re Quinlan*, 70 N.J. 10, 355 A.2d 647; a discussion of the case and its role in the emergence of the substituted judgment standard in surrogate healthcare decisionmaking can be found in Meisel, 268-271.

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27. Superintendent of Belchertown State School v. Saikewicz, 373 Mass. 728, 370 N.E.2d 417; for discussion of the case and its relevance to the substituted judgment standard, see Meisel, 270-273, and Beauchamp and Childress, 171-173, and 522.


29. This case study is one from the personal file of this author compiled while in clinical ethics practice. The situation of the surviving spouse, usually wife, in the position of consenting to treatment limitation that will result in the patient's death is not unusual in itself. The reason this case was chosen for inclusion out of a file of hundreds is that it clearly demonstrates how behavioral norms regarding consent can erode the patient-family-professional triadic relationships and cause rather than ameliorate further suffering.

30. NRS 449.626 states that "1) If written consent to the withholding or withdrawal of the treatment, attested by two witnesses, is given to the attending physician, the attending physician may withhold or withdraw life-sustaining treatment from a patient who: a) Has been determined by the attending physician to be in a terminal condition and no longer able to make decisions regarding administration of life-sustaining treatment; and, b) has no effective declaration. 2) The authority to consent or to withhold consent under subsection 1 may be exercised by the following persons, in order of priority:" (see note #26).

31. Ibid., #4 states: "A decision to grant or withhold consent must be made in good faith. A consent is not valid if it conflicts with the expressed intention of the patient."

32. This also is a case study from the personal file of this author.

33. See note 31.
CHAPTER 2

FOUNDATIONS OF THE DOCTRINE OF INFORMED CONSENT

The notion of informed consent as the basis for decisionmaking in healthcare, one of the primary tenets of contemporary U. S. medical ethics, is a relatively recent and particularly Western phenomenon, the result of a multidimensional process involving philosophical, political, legal, social and cultural influences. Few if any of the classical documents of early Western medicine contain a notion of the concept of autonomous decisionmaking by the patient. On the contrary, decisions concerning the proper course of action regarding a patient's treatment had been considered largely the domain of physicians.

This chapter will consider a brief history of the development of ethics in Western medicine and the development of the doctrine of informed consent in contemporary U. S. medical ethics. It will begin with early conceptions of the role of the physician in patient-physician interactions and proceed to contemporary times. The intentions are to identify and clarify the developmental influences leading to the contemporary notion of informed consent for healthcare decisionmaking. These influences come from a variety of sources and include the following. First, early roots of an ethos for the practice of Western physicians are traced to ancient Greek understanding of the purpose and practice of what was considered a sacred oath of service to the sick. Second, changes in that ethos...
affecting patient-physician interactions are shown to derive from Christian cleric-physicians whose role was closely linked to divine authority. Third, as liberal political ideas of the Enlightenment were shaping Western conceptions of the self and individual freedoms, the medical profession failed to meaningfully reflect those conceptions in their attempts to further define their professional role in patient-physician interactions. However, public acceptance of the same liberal conceptions of the self in the context of medicine led to growing legal support of the patient's right of self-determination. This support was articulated through the emerging legal doctrine as the importance and necessity of informed consent for healthcare decisionmaking. Fifth, dramatic scientific and technological advances in medicine and public evidence of Nazi medical experimentations on prisoners prompted critical examinations of ethical conduct for medical research involving human subjects in the post-World War II era. This critique resulted in the development of ethical standards for Western medical researchers. Sixth, despite these ethical standards, blatant disregard by U. S. researchers was revealed, generating public outcry and resulting in U. S. legislation intended to protect human patients and subjects by forcing compliance with established ethical research standards. Finally, a remnant of Anglo-American past, that of early settlers with a strong religious belief in moral rules for guiding actions, is found in twentieth century medical and biomedical ethics as a grounding for resolving conflicting rights. All of these influences on U. S. medical culture converged in the second half of the twentieth century to result in the development of what is now largely accepted as the necessary participation of patients in medical decisionmaking through informed consent.
Early Western Medicine

Western medical practice, including its ethics, is usually traced to ancient Greek origins, particularly The Oath and other Hippocratic writings rooted in the religious sect of Pythagoreanism, rather than philosophical writings. Indeed, philosophy was not formally involved in developing medical ethical standards of practice until the late twentieth century.¹ The early practice of medicine was primarily a healing art, combining the limited tools of the time and the patient's natural healing energies with the healing presence of the physician. Medicine was understood to have specifically limited purposes. Medical interventions of the time were expected to relieve the distresses of illness and sometimes cure the ailment. The practitioner was expected to know not only what actions to take to relieve the patient's condition, but also when not to intervene, as in the case of very advanced disease. This was because the physician "know[s] everything is not possible to medicine."² Thus, the contemporary notion of success in medicine as equated with cure was more a notion of comforting care, skillful use of knowledge and tools, healing presence working together with nature, and an understanding of the limitations of medicine.

The Hippocratic Oath should be understood as a pledge to attend to the needs of patients as best one can, without causing undue harm in the process. It proposes, "to help the sick to the best of my ability and judgment...[and] abstain from harming or wronging any man...."³ This part of the Oath has been used as the basis for a claim to beneficence in the grounding of physician interactions with patients. Interpretations of beneficent actions have been debated in more recent times. Beneficence has been interpreted as
condoning patient deception and disregard for a patient's preferences of treatment under the guise of benefitting the patient to "the best of my ability and judgment." Similarly, the Oath makes no reference to a physician's obligation to converse with a patient. Indeed, it gives explicit advice on "...concealing most things from the patient while you are attending to him...revealing nothing of the patient's future or present condition...." This, too, has historically been used to condone what has been called beneficent deception, or the practice of concealing a patient's diagnosis or prognosis under the guise of protecting the patient from psychological harm. The perspective of the patient regarding these practices does not enter into the considerations or judgment. In the Hippocratic school of medicine, illness was the result of natural causes, rather than "divine retribution, the invasion of demons, or the disturbance of evil spirits." Rational reasoning based in observation of the senses was the primary tool of diagnosis. As revolutionary as this was in the movement of medicine from a mystic practice to a scientific process, it was also the beginning of what was to grow into a chasm of silence between patient and physician, breaking their relationship in two, separating the fundamental interrelationship and interdependence between healer and patient. For these reasons, the Oath can be criticized as justification for paternalistic practices in medicine, in particular a lack of meaningful communication between physician and patient.

As the Western world moved into the medieval era, much of the practice of Western medicine was done by religious clerics of the Catholic Church dedicated to the service of the sick and caring for the great numbers of wounded from various religious wars, most notably the Crusades. Cleric-physicians followed the tradition of practitioners stemming...
from the Greek religious sect of Pythagorianism. The Hippocratic Oath continued as a pledge of service to the sick for these Christian physicians. To be acceptable to the Church the Oath needed only minor revisions, such as the exclusion of references pledging loyalty to goddesses and gods.

Following the Oath's pledges, conversations between these cleric-physicians and their patients were no more open than in ancient times and primarily served the purpose of offering hope, comfort and reassurance. However, sometimes the only hope of the patient's survival required convincing the patient to endure the often crude, unpleasant treatments and medicines of the time. Such an objective required an emphasis on the need of the physician to be authoritative or even manipulative, because without respect for medical authority and so adherence to its prescriptions, there often was little chance of recovery.

During this period, interactions between physicians and patients were shaped by three beliefs, stemming primarily from the association of the practice of medicine with the clergy of the Church. These beliefs were that: patients must honor physicians because as clerics they received their authority from God; patients must have faith in their physicians because as clerics they are the servants of God, therefore faith in cleric-physicians reflects their faith in God; and, patients must promise to follow the prescriptions of their physicians as they would follow the laws of the Church because they come from God's servants. Under this religious influence, medical practitioners and the lay public alike developed the idea that, in matters of their practice, the physician's authority was absolute because it was God-given. Although service remained part of the role of physicians, the
authority of the physician took on another dimension of importance. This shaped the way in which patients and physicians related. Physicians were eventually seen as having authority over patients, and patients were seen as having a duty to be faithful in obeying that authority. Thus, within this context the importance of physician-patient dialogue or shared participatory decisionmaking was not considered.

**Early Western Medical Ethics**

During the eighteenth and nineteenth centuries secular ethical theories and philosophy began to influence the practice of medicine. Yet the impact on patient-physician relationships and respect for patients as sentient beings remained at the fringes of medical practice. The new scientific methods for investigation in the natural sciences and its reliance on reproducible evidence were taking hold in many areas of scientific research. Applying the new science to medicine meant that causes of illness and the effectiveness of their treatments could be more reliably proven and reproduced, making the practice of medicine more certain than in the past. Claims of objectivity and reproducible scientific research outcomes were viewed as a means of legitimizing scientific medical practices and exposing non-scientific practitioners as charlatans who did not have similarly reproducible foundations for their claims of successes. Thus, scientific medical practice claimed itself as more reliable than other methods of practice.

In 1772 Dr. John Gregory wrote about the moral purpose of medicine as the preservation of the patient's best interest through "...preserving health...prolonging life and curing diseases." Gregory loosely supported a moral obligation of the physician in
truth-telling, but did not go so far as to endorse emerging political ideas regarding the balance and conflict between paternalistic beneficence and personal autonomy. Physicians were still viewed as the appropriate authority on patients' best interests. Ultimately, Gregory's ethics did little to further the participatory decisionmaking of patients in their own healthcare. Rather, he continued support for traditional physician beneficence over patient autonomy, based in part on new claims of expanding esoteric knowledge of physicians.

Early in the nineteenth century Thomas Percival's book on medical ethics became another foundation for Western physician ethics. However, it focused on ethics in health care from the perspective of physician relations with hospitals and other healthcare professionals, and dealt primarily with social etiquettes. He supported this idea that the preferences of the patient were not to be harshly opposed. He did so not because patients deserved respect as sentient beings or because patients had the right to make their preferences known. Rather, he did so out of considerations for therapeutic outcomes. Nineteenth century physicians held essentially holistic beliefs in the importance of involvement of the whole person for therapeutic healing. The modern era of medicine as a scientific practice, concerned primarily with the functioning and disfunctioning of the body resulting from illness and injury, had not yet taken complete hold. Similarly, the concept of mind-body dualism, in which mind and body are viewed as disconnected and functioning separately, was not yet part of medicine. For Percival and his colleagues, a person's mental state could directly affect physical well-being, and thus the patient's treatment preferences should be considered. Since behaviors such as ignoring or
overriding the wishes of the patient could create fear, anxiety, resentment, or anger, and these emotions were recognized as detrimental to recovery, such behaviors were not advocated. However, Percival's ethics continued to follow the traditional thinking that physicians should be ministers of hope and comfort to the sick, and so urged restraint in making grim prognostications regardless of knowledge to the contrary. Although he acknowledged the patient's right to know the truth about an illness, Percival argued that the physician's obligations to benefit the patient superseded that right. So he too ultimately supported what was claimed to be the physician's appropriate authority of benevolent deception in patient-physician interactions, information and best interests decisions.

Shortly thereafter the newly formed American Medical Association (AMA) published its first Code of Ethics in 1847. It was unmistakably similar to Percival's and remained largely paternalistic, supporting physician authority and beneficent deception in treatment decisions even after several revisions. Thus, regardless of holistic approaches to mind-body interactions in illness, what was rapidly becoming an institutionalized practice of medicine sanctioned the notion of physician authority in the name of beneficence concerning patients' best interests. In supporting this notion of authority as appropriate in the role of physicians interacting with patients, the AMA sanctioned physician power over patients in their determinations of when to adhere to patient preferences, when to lie to patients, and when to manipulate or withhold the truth. In this way, physicians placed themselves at the center of relationships with patients, unilaterally controlling interactions and decisions. The importance of patient involvement in decisions concerning their own
body, tied to self integrity, remained outside the purview and practice of medicine.

There were a few scattered instances of evidence that a rudimentary notion of informed consent existed prior to the mid-twentieth century. Two physicians of the nineteenth century, Worthington Hooker and Richard Cabot, have been cited as isolated individuals who fought against the practice of beneficent deception. Neither, however, recognized informed consent as obtaining the patient's permission or respect for the patient's autonomy. Rather, it was considered merely expedient to disclose truth to a patient regarding the patient's illness. Thus, physician authority in the name of beneficence continued to control the power in relationships and interactions with patients. The art of healing, a practice which requires the knowledge and energies of both patient and practitioner working toward the mutually understood best interest of the patient, remained outside the practice of medicine.

**Modern-Era Political-Philosophical Influences**

Late in the seventeenth century liberal political philosophy with its emphasis on individual rights and freedoms was beginning to gain prominence the Western world. Thomas Hobbes and John Locke are two of the early writers credited with promoting the concepts of individual rights and of social contracts as the basis of the formation of governments. According to Hobbes, it is the human characteristic of reason which allows for the social contract of agreement for order among those within a society. Governments are formed in order to protect the mutual rights of all its individual members and punish those who would infringe upon the rights of others. It is from the
social contract that the secular morality of a society emerges. According to Locke, natural rights such as life, liberty and property belong to all persons and are not given up to a government. Rather, only the right to judge and punish infractions of the social order is given up to the government. Locke's theories of fundamental rights of individuals and contract ethics provided the new United States and other nations with an ethico-political framework for the development of such documents as the Declaration of Independence and the Bill of Rights. It was also clearly a source of influence on the acceptance, furtherance and elevation of notions of rationality and impartiality as the hallmarks of liberal rights which later played instrumentally in the development of contemporary U. S. Bioethics.

Nearly a century later, Immanuel Kant laid the foundation for the concept of autonomy which was much later applied to medical contexts. According to Kant, morality is motivated by duty. He viewed morality as rules or laws which, as in nature, are universal to all rational beings. He argued that what is right or wrong in a particular situation can be determined by eliciting the maxim or principle of an action and asking whether it can be consistently willed in universal adjudication. This requires that every person be regarded as an end, not as a means, and all of mankind as a community of ends. Kant also argued that freedom is an indispensable basis for morality. Free will, as a requirement of practical reason, is implicit in the moral judgment that a person could have acted otherwise, and without it one could not be blamed for one's action. The idea Kant formulates is that of autonomy, that is to say moral law is imposed by the practical reason (will) of rational beings. This contrasts morality based on desires of human beings.
rather than religious command. Thus Kant’s conception of autonomy is a kind of self-determination in which self-will, as practical reason, both creates the moral law and chooses an action out of a rational respect for that moral law. Kant’s autonomous agent must be motivated by duty to the moral law, completely untainted by personal inclinations such as self-interest, pursuit of happiness, love of another, sympathy or emotional reaction. It is the view of the solitary and isolated self-actualized individual. It is a view of the self that can be criticized as the view from nowhere because it is a self who is not situated within a context. Still, the profound influence of the application of interpretations of Kant’s autonomous person and actions in the development of contemporary ethical theory regarding informed consent and decisionmaking cannot be overestimated. It is the interpretation and application of Kantian notions of autonomy in contemporary medical ethics context that has been at the heart of emerging problems in judgments by physicians of patients’ autonomy for informed consent and medical decisionmaking. This is likely due to codification of informed consent and an expectation that clinicians interpret a philosophical concept for which they are ill prepared and about which they have conflicting interests.

In the nineteenth century John Stuart Mill wrote his political essay, On Liberty, which is considered a classic philosophical source for antipaternalism in the state and for medical ethics as well.15 Mill argues that only when harm is caused to another is there legitimate grounds for intervention with a person’s autonomous choices and actions. Unfortunately, Mill has not had quite as great an influence on physician interactions with patient decisionmaking as Kant. Further, like Kant’s theory of autonomy, Mill’s concept
of noninterference applied to the medical context also requires that healthcare professionals interpret the autonomous choices and actions of patients. So it presents a similar problem in the judgment of another’s autonomy for the purposes of decisionmaking.

The works of Locke, Kant, Mill and others greatly influenced the development of American liberal politics. Individual rights and freedoms gained importance in the emerging new government and shaped its foundational documents, the Declaration of Independence, the United States Constitution and the Bill of Rights. These documents further influenced the development and popularity in the U. S. of such concepts as rationality, individual autonomy and self-determination, which were later applied within the context of medical decisions. The concepts, although originally conceived in reference to the political state, also had significant influence in the development and dominance of the most prominent principles of medical ethics. Under such influence, in philosophical debates between the principles of beneficence, usually understood as traditional paternalism, and autonomy, usually understood as self-determination, autonomy was given primacy. Thus it followed in medical ethics that autonomy of the individual became a primary consideration and served as the foundation for the development of legal recognition of a right to self-determination in medical treatment, and establishes the importance of informed consent in assertion of that right.

U.S. Judicial Influences

The importance and relevance of these political principles to the U. S. medical ethos
was reinforced in the courts as patients challenged the authority of physicians with the authority of self-determination. Beginning in the 1890s, U.S. courts were faced with cases brought by patients who claimed to be the victims of involuntary surgery. These claims were different from earlier cases in that they not only charged the physician with malpractice but also with battery, based on the right to privacy and against unwanted touching. In this way, the courts were drawn into the beneficence/paternalism versus autonomy/self-determination debate. The judgments ultimately reflected the growing political sentiments of the primacy of autonomy and self-determination to the lay public as applied to medical interactions. In 1914 the decision against the defendant in Schloendorff v. Society of New York Hospital included the statement by New York Supreme Court Justice Benjamin Cardozo that "...every human being of adult years and sound mind has a right to determine what should be done to his own body; and a surgeon who performs an operation without his patient's consent commits an assault...."\(^{15}\) This case is often cited as the precedent for charges of battery against physicians in cases where consent, usually for a specific surgery or procedure, was not explicitly obtained. Judge Cardozo's statement is often quoted in affirming the absolute necessity of obtaining the patient's explicit consent prior to any major, non-emergent medical intervention. Herein is the beginning of the emergence of the legal doctrine of informed consent, and the legal recognition and importance of the right of self-determination.

Until the mid-twentieth century, the courts usually regarded self-determination in the requirement of consent as consisting of the patient's agreement to a proposed invasive procedure, usually surgery. Most often this was accomplished by the physician telling
the patient what was proposed and why, usually in a manner that would virtually guarantee patient agreement with the plan. Because of this, what was called consent could more accurately be understood as assent. Considerations of what the patient should know in order to agree had not been defined. Salgo v. Leland Stanford, Jr., University Board of Trustees in 1957 was the first case to apply the additional requirement and emphasize the importance of specific information regarding potential risks as an essential element of medical consent. It was in this case that the phrase "informed consent" was first used.\textsuperscript{16} The court further stated that any discretion used in the disclosure of potential risks based on the assessment of the patient's mental and emotional state must be consistent with full disclosure of the facts necessary to make an informed consent. Thus the courts were starting to define the extent and kind of information necessary for assertion of the right of self-determination in healthcare decisionmaking.

Shortly thereafter, in 1960, the decision in Natanson v. Kline further defined disclosure of information as the necessity of revealing treatment hazards that should be reasonably known to all physicians. This became known as the "reasonable doctor" standard. The standard was redefined in 1972 in Canterbury v. Spence to include the necessity of revealing risks that an unidentified but universal, reasonable person would want to know. Although this created problems in determining who this reasonable person was and exactly what he or she would want to know, nonetheless this case moved the emphasis of who should be the one judging the kind of information needed for decisionmaking from the physician to the patient, and became known as the "reasonable patient" standard. Thus the philosophical principle of respect for autonomy was
developing considerable weight due to progressive support in the emerging legal doctrine which required a specifically defined notion of informed consent. The courts further articulated the legal rights of privacy, protection from unwanted touching, and self-determination as the right to make informed decisions regarding one's own body within the context of medical treatment. As the reasonable patient standard governing the kind and amount of information necessary for informed consent moved into rights language, the focus changed from kinds and amounts of information, to an individual's right to information, any and virtually all information, based on the requirements of the individual asserting the right.

Despite the progressive assertion of self-determination in early theoretical medical ethics and the law, physician clinical practices and attitudes remained paternalistic regarding information and claimed beneficence in interactions with their patients. A study by Louis Harris, et al., in 1982 demonstrates an inconsistency between the legal and theoretical doctrine of informed consent and actual physician practices and understanding of informed consent. The overall impression conveyed by this survey is that while physicians reported seeking patient consent, they had something quite different in mind than an autonomous act by the patient. In their survey, the authors reported that in answer to the question, "What does the term informed consent mean to you?" only 26% of the physicians queried indicated that informed consent had anything to do with a patient giving permission, consenting or agreeing to treatment. In addition, only 9% indicated that it involved the patient making a choice or stating a preference about treatment options. The overwhelming majority of these physicians appeared to recognize
only the information-giving component of informed consent, or the duty of disclosure. They viewed informed consent as explaining the nature of the condition and treatment so that the patient understands what is or will be taking place. To these physicians, informed consent means only *telling* things to patients, not *asking* anything, such as permission. Based on this kind of evidence, it would seem that as late as 1982 all that was understood by many physicians about informed consent was that the patient's signature was required on a "consent" form after some kind of disclosure had been made, rather than any meaningful exercise of informed choice. It would also seem that the legal underpinnings of informed consent in the duty to disclose relevant information, rather than the philosophical underpinnings of respect for a patient's self-determination, had a more substantial influence on the actual practice of informed consent in medicine.

This points to an ongoing and pervasive inconsistency in the practices and attitudes of physicians with the formal medical and public acceptance of the importance of informed consent. The basis of this inconsistency lies in the paternalistic notions that the physician could know what is in the best interests of the patient without consulting the patient, and that claims of beneficence could justify overriding the patient's view of best interest if it did not coincide with the medical view of the patient's best interest. The notion that this disregard for the patient's self knowledge is not beneficence but a kind of rationalization for imposing the medical view as absolute power over patients who seek care and treatment is not understood. This imposition goes beyond confidence in one's expertise and esoteric knowledge and clearly disregards the essence of medicine as a healing art. The art requires humanistic skills beyond esoteric knowledge and use of tools. It requires
an interplay between healer and patient, including the knowledge, energies and
interdependence of both. It requires building mutual trust, understanding and respect.
Finally, it requires recognition and acknowledgement of one's own humanity in the other.
None of these are evident in claims of paternalistic beneficence. Indeed, such claims are
essentially antithetical to a healing art.

Western Social, Technological and Scientific Influences

Alongside the development of liberal political concepts of individual autonomy and
self-determination and their applications in medical contexts, came the developments of
science and technology. During the Industrial Revolution technological advancements
were closely followed by significant scientific breakthroughs, which often resulted in
more technology. The discipline of medicine made progress in improved diagnostic and
treatment measures and soon came to place a much higher value on the empirical science
of medicine over what had previously been considered the healing arts. As medicine
mirrored the values of U. S. industrial society, and as technology and science made
medical "miracles" possible, the earlier Greek and medieval notions of the humanistic art
of healing fell by the wayside. By the mid-twentieth century the scientific and
 technological paradigm which now pervades every aspect of our daily lives had become
firmly rooted in U. S. society. As medicine took on the dual powers of science and
technology, physicians moved farther and farther from the bedside and the patient.
Similarly, as the influence of the legal system increased, the U. S. public became
enamored with rules of conduct, individualism, and laws governing relationships and
behaviors.

The development of contemporary U. S. medical and biomedical ethics with its particular emphasis on autonomy, self-determination and informed consent is often traced directly to the post-World War II era. Following the Second World War, as evidence and testimony revealed the details of Nazi doctors' experimentation on their prisoners, the U. S. together with its Western allies began to consider the ethical aspects of medical research and experimentation on human subjects. The Nuremberg Code of 1946 created an international voice regarding the importance of the patient's agreement to medical interventions, particularly medical experimentation.

This Code, a result of the Nuremberg Military Tribunal's deliberations in the case of the United States v. Karl Brandt, et al., is a ten point statement of permissible conditions for medical research on human subjects. It begins, "The voluntary consent of the human subject is absolutely essential." The Code specifically advocates that the subject should have legal capacity to consent; should be able to exercise free power of choice "...without the intervention of any element of force, fraud, deceit, duress, ...or other ulterior form of constraint or coercion...;" and should have sufficient knowledge and understanding of the information regarding the elements of the research in order to make "...an understanding and enlightened decision." The detail of the information necessary for this type of decision entails,

...the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonably to be expected; and the effects upon his health or person which may possibly come from his participation in the experiment.\[9]
Responsibility for determining the quality of the subject's consent is also clearly assigned to the researcher. Thus, the Code sets the stage for the formal adoption of what is currently considered the necessary elements of medical research informed consent.

In 1962 the first Declaration of Helsinki was developed and adopted by the Eighteenth World Medical Assembly at Helsinki, Finland. Their purpose was to reaffirm the importance of ethical considerations and protection of human subjects in medical research. Revised in 1975, the Declaration explicitly addresses the importance of the researcher’s responsibility in assessing predictable risks and benefits to the subjects of the research, and in abstaining from research where the risks are found to outweigh the benefits. Information regarding the "aims, methods, anticipated benefits and potential hazards of the study and the discomfort it may entail" must be part of each subject's consent to participation. In addition, the researcher is expected to inform the subject that he or she is free to not participate in the study, or free to withdraw at any time. The researcher is advised to be particularly cautious regarding the subject's consent if the subject is in a situation or under duress that could influence the free nature of the consent. The Declaration also requires that researchers recognize those who do not have capacity for consent, and, if they are to be included in the study, must provide for them to receive the same information and obtain consent through a legal guardian or authorized relative.

At the 1966 Annual Convention of the American Medical Association (AMA) the House of Delegates formally adopted the ethical principles endorsed in the first Declaration of Helsinki in 1964. The guidelines the AMA subsequently published for its members enlarged upon those in the Nuremberg Code and the 1964 Declaration of
Helsinki. In 1974 the AMA was asked to establish procedures for the protection of the rights of those potential research subjects who were mentally incapacitated and institutionalized. The AMA House of Delegates reaffirmed the 1966 guidelines, emphasized the ethical responsibility of the researcher, endorsed the principle that the rights of those subjects whose ability to consent is impaired must be protected, and affirmed the goal of establishing international uniform standards and procedures, including informed consent, for medical research.

Several specific events in technological development and medical research in the United States increased the acceptance by the public of the importance of informed consent. These technological achievements included the developments of artificial ventilation techniques for acute respiratory failure in the 1950s; hemodialysis for renal failure, with methods of patient selection by committee for its limited availability in the early 1960s; the initiation of organ transplant surgery with kidney transplants in the 1960s, and later, heart transplants in 1969.

However, in addition to these technological advancements, the 1960s marked the beginning of public awareness of research consent violations with the uncovering of significant omissions of consent in medical research within the United States. The post-World War II activities of the United States and other countries had resulted in the codification of world-wide agreement on ethical behavior for medical researchers through the Nuremberg Code and later the Declaration of Helsinki. But the actual behavior of medical researchers regarding informed consent was not aligned with these expectations of ethical researcher conduct. What was revealed, and continues to be revealed, can be
considered a pervasive disregard for these codes of ethical behavior by researchers in practice. Henry Knowles Beecher, a professor at Harvard Medical School, has been widely acclaimed as having taken the lead in investigating and exposing the actual practices of medical researchers. He published a groundbreaking article in 1966 and subsequent book in 1972 on his analysis of researcher practices regarding informed consent of their subjects. He cited twenty two examples of researcher misconduct in risking the health and/or life of their subjects, without informing them of the dangers of the experiments or obtaining their permission through informed consent. Beecher concluded that unethical or substantially questionable conduct among researchers was not uncommon. Further, he noted that these breeches of conduct were not limited to private institutions or funding programs, but also occurred in prestigious medical schools, government military departments, the Veteran's Administration Hospitals, and federal agencies such as the National Institutes of Health.  

One of the first of these incidents occurred at the Jewish Chronic Disease Hospital in New York. A research project initiated in 1960s was conducted at the hospital in which twenty-two patients were injected with live cancer cells. The objective of the study was to determine whether the cause of a decline in the body's inability to reject the transplanted cells was due to the cancer cells or to the patient's debilitation. Patients without cancer were needed for the study. Some of the patients were informed verbally that they were involved in a medical experiment, but they were not told that they were to be injected with cancer cells. No written consents were obtained, and some of the subjects were incapable of giving consent. The incident was eventually brought to court
and the participants were found guilty of fraud, deceit and unprofessional conduct.\textsuperscript{24}

Another incident of disregard for codes of ethics in medical research in the United States occurred in New York at Willowbrook State School, a state run institution for children with mental disabilities. A series of experimentation began in 1956 with the objective of developing an effective prophylactic agent for infectious hepatitis. The researchers deliberately infected patients with strains of hepatitis after consents were obtained from parents of the children under circumstances that may have been manipulative. Although the experiments were eventually disclosed in 1972, closure on the debate over the ethics of the research was never achieved.\textsuperscript{25}

One of the most well known cases of blatant disregard for research ethics was that of the Tuskegee syphilis study. The Public Health Services initiated a study in the 1930s to compare the effects on health and longevity of untreated syphilitic persons with nonsyphilitic, otherwise similar persons. The subjects were all African American males who did not know the name or type of their disease. They were only told that they were receiving free treatments for "bad blood," a term that was allegedly assumed by the white physicians a euphemism for syphilis. One of the most compelling elements of the situation was that the research was repeatedly reviewed by Public Health Services officials and medical societies, reported as articles thirteen times in respected medical and public health journals, and yet continued without challenge until 1970. Once revealed as a concern regarding research consent ethics, the Department of Health, Education and Welfare appointed a panel to investigate the policies and procedures for department protection of human subjects. What the panel concluded was that no governmental
agency had an adequate policy for reviewing research procedures or for securing the consent of subjects.\textsuperscript{26}

As a result of these exposures, and their profound effect on the public consciousness regarding ethical issues and behaviors in medical research and clinical practice, interest in the ethical implications of the applications of medical technology and research grew. The Hastings Center and the Kennedy Institute were started in 1969 and 1970 respectively. Their primary purpose was to provide a forum for discussions which the founders hoped would bring moral clarity into the complex, confusing and conflictual situations created by the advances in medical science, and to examine the ethical and moral implications of rapidly expanding medical technologies. Both of these centers remain actively involved in the on-going dialogue regarding these issues today. Discussion and debate surrounding informed consent, surrogate decisionmaking, considerations of family and community, and the appropriate role of healthcare professionals remain central issues in U. S. medical ethics today.

As the twentieth century closes, evidence that a scientific ethic in medical treatment and disregard of patient preferences by physicians continues and is pervasive has been recently documented in the SUPPORT study. This four year study focused on physician-patient communication, frequency of aggressive treatment, characteristics of hospital deaths, and related interventions for specific outcomes. The results of this study demonstrated that the structured interventions designed to change physician behaviors in these areas through improved communication were, for many reasons, ineffective in all areas of focus.\textsuperscript{27} The published report on these outcomes shocked much of the lay public.
yet confirmed the anecdotal suspicions and experiences of many healthcare practitioners.

**U.S. Regulatory and Legislative Influences**

In addition to professional discussions and examination of these issues within think tank organizations, the federal government also got involved. Congress passed the National Research Act and established the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research in 1974. This Commission's task was to devise ways to protect the rights and welfare of human subjects of research, and to study the ethical principles that should govern biomedical research. The commission was specifically directed to consider

- the boundaries between biomedical and behavioral research and the accepted and routine practice of medicine;
- the role of assessment of risk-benefit criteria in the determination of the appropriateness of research involving human subjects;
- the appropriate guidelines for the selection of human subjects for participation in such research and the nature and definition of informed consent in various research settings.

The commission produced the Belmont Report which applied the ethical principles of respect for autonomy, beneficence and justice to biomedical and behavioral research. It represented the first official governmental analysis of the ethical principles that underlie medical science and medical decisions from the standpoint of a secular, nonprofessional body.

Following the conclusion of the National Commission, the President's Commission on the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research was appointed in 1980. Its mandate was broader and included issues about care of the dying, genetics, decisionmaking, informed consent, and the allocation of scarce...
healthcare resources. The Commission produced multiple reports, considered by some to be the standard for secular medical ethics, with three volumes devoted to issues surrounding healthcare decisionmaking and informed consent. These volumes argued that although the history of informed consent emerged primarily from law, its requirements are essentially moral and policy oriented. It further argued that informed consent is based on a principle that competent persons are entitled to make their own decisions from their own values and goals. Thus, for a consent to be valid it must be derived from an active, shared decisionmaking process between the physician and the patient. The Commission described the principle of self-determination as the foundation of its viewpoint. It seems clear that the viewpoint of the Commission and that of physicians reflected in the Harris study were not just inconsistent, but coming from opposing views, one focusing primarily on patients and their involvement in decisionmaking, and one focusing primarily on physicians and their legal liability.

By 1990 the combined effects of the published works by these two Commissions, heightened awareness concerning individual freedoms and publicity surrounding legal cases resulted in public recognition and wide support for the rights of patients to make their own healthcare treatment decisions. These rights were recognized not only in the present situation of patients, but for an unforeseen yet possible future as well. This growing perspective included that healthcare providers should recognize and uphold those decisions.

The Patient Self-Determination Act (PSDA), passed as part of the Omnibus Budget Reconciliation Act (OBRA) of 1990, became effective in December, 1991. The passage
of this bill by Congress was influenced in part by the Supreme Court decision in the
*Cruzan* case and the national publicity surrounding it. In *Cruzan*, the family of Nancy
Cruzan, a young woman who remained in persistent vegetative state (PVS) for several
years following a car accident, requested that her physicians discontinue the tube feedings
that provided life-sustaining treatment for Nancy. The family maintained that she would
not have wanted to live in a PVS condition for the unknown remainder of her life. The
physicians and the institution refused to comply based on the position that to do so would
cause her death, and since she was unable to communicate in any way, there was no
means to obtain her direct agreement. Through the publicity of the anguish of the family
in the circumstances of the case, the Cruzan family brought into focus the plight of
persons who no longer have the mental capacity to make their own healthcare decisions,
and thus could be subjected to sustained medical treatment they may not have wanted.
The case also brought to public light the reality of contemporary medicine's capabilities
to prolong biological life without the likelihood of recovery or return to previous
function. Although not entirely unique in itself, the case fueled public interest in medical
decisionmaking because it exemplified what many persons felt was a fate they would not
want to suffer themselves.

The PSDA was passed with the intention to empower individuals to take part in the
medical decisions that affect the duration and condition of their lives. Its sponsors,
Senators John C. Danforth and Daniel Patrick Moynihan, wanted to correct what was
perceived to be an imbalance of power in healthcare decisionmaking and clarify the
relationship between patients and healthcare providers regarding who was the proper
decisionmaker. According to Senator Danforth, this imbalance had swung toward "neglecting the caring component of medicine and trampling on the rights of patients." This statement reflects a growing concern on the part of the public that the direction of contemporary medicine and its providers had left too far behind the therapeutic healing relationship once an intrinsic part of the art of medicine.

Passage of the PSDA did not end the problems with physician recognition and support of the self-determined healthcare decisions of patients as was intended. The four year SUPPORT study has recently demonstrated that in reality many patients in healthcare institutions experience their last few days of life at the hands of practitioners who do not know their patients' preferences and do not adhere to the details of those preferences when they are known, and spend much of their last few days on mechanical ventilation, comatose, or in significant pain.

There have been many analyses of the results of the study from different perspectives. However, one of the problems that is central to the intent of the PSDA is that of constructing a legal or regulatory answer to what is in essence a moral problem. What the PSDA intended and mandated through Advance Directives was to enable individuals to prospectively direct their own future healthcare when facing end of life medical care in the event that they are incapacitated to do so at that time. This kind of event, in which a person is facing one's own death, treated with medical science and technology that they would not choose but is unable to voice one's preferences to stop, is a deep fear of many individuals, fueled by the situations of Nancy Cruzan and many others. Another intent of the PSDA was to give formal recognition to the philosophical concept of the expression
of a person's autonomy through the act of self-determination. This recognition seemed most important in the context of healthcare where one's preferences concerning life, death, bodily invasions and medical authority seem to converge.

It was assumed that the way to best support individual preferences and change the paternalistic habits of clinical medical practice was to require practitioners to honor these preferences through legislative action. However, as the SUPPORT study demonstrated, the mere act of signing an advance directive, or communicating preferences through a proxy once unable to do so is insufficient and fails to capture the complex nature and imbalance of power in healthcare interactions. It further exemplifies the difficulty in trying to legislate what is essentially a moral problem within the practice of medicine. The SUPPORT study sadly shows that the attitudes and behaviors of physicians in medical practice in healthcare institutions has changed very little since the Harris study of 1982. As long as the profession of medicine and all healthcare professionals do not view their role and relationships with patients as derived from a humanistic art and related skills, the moral problem of respect for persons as sentient, whole beings will continue.

A Cultural Influence

Contemporary U. S. medical ethics and its use of principles developed under a cultural influence as well. Albert Jonsen has suggested that an influence can be traced to moral thinking rooted in the Calvinist-Augustinian traditions of early American settlers. That thinking deeply believes in clear, unambiguous moral principles, and in the importance of the observance of these principles for the common good. According to
Jonsen, this particular culture viewed the world in antithetical categories, and sought boundary systems and patterns of control that could hold moral order against the potential of moral disorder. He argues that this morality survives today in dominant contemporary U. S. culture to some extent, in form if not exactly in content. It has resulted in what Jonsen calls "secular fundamentalism," that is, rules and principles for guiding right actions which are strictly adhered to but no longer attached to orthodox religious rationale and sanction. It is this thread of an early fundamentalist moral tradition in the historical past that was subsequently adapted to the use of secular philosophical principles and applied in the context of healthcare decisionmaking and the use of medicine.

The notion that moral principles could be used as guiding rules, combined with a liberal political ideal of individual autonomy and medical-legal events, has had significant influence on the struggle to define contemporary U. S. medical morality. As this definition began to take shape, U. S. medical ethics developed into principlism. In moral systems utilizing multiple rules for conduct, an informal hierarchical order emerges when those rules are in conflict. It is the same with principlism in medical ethics. The principle of respect for autonomy, articulated as self-determination and informed consent, was elevated to the position of primacy which it now holds in healthcare decisionmaking. This primacy served to institutionalize a philosophical view of the autonomous individual that was claimed to be a universal value. Autonomy, as interpreted in predominant contemporary bioethics literature, became a particular standard by which all patients were judged by healthcare professionals regarding their capacity for decisionmaking, and which all patients were assumed to value. The consequences of institutionalizing such a
particularized view of values within the context of personal healthcare decisionmaking has led to the kinds of problems with informed consent presented in Chapter 1.

Conclusions

Early conceptions of a medical ethos concerning a proper relationship and interaction between patient and physician held the notion that the physician was bound by an oath of duty to serve the needs of patients in the patients' best interests. Medicine was a healing art, and as such, required the combined knowledge, skills and energies of both patient and physician. Although the notion of informed consent was not a part of that ethos, neither were patients disregarded as passive participants in or recipients of the healing process and the use of medicine. The therapeutic effects of the powerful healing forces of nature within the patient were well acknowledged and respected. Yet even as the art of healing in early medicine engaged the physician and patient together, the physician's oath and its application in practice were also the earliest sources of what was to become a chasm of silence in and within the relationship between patient and physician.

As early Hippocratic physicians gave way to Christian cleric-physicians, the role of the physician gradually took on the dimension of divine authority, linking cleric-physicians as servants of God with the authority of God. This authority set physicians apart from patients and strongly reinforced paternalistic beneficence as the guiding principle for physician attitudes and behaviors in interactions with patients. As scientific knowledge in medicine advanced, the art of healing was left behind in favor of the presumed superiority of science. At the same time the silence grew, fed by increasing
esoteric knowledge and a paternalistic belief in deceptive beneficence.

As Western liberal political ideas influenced the public conceptions of the individual, self and liberty, the application of these conceptions in the context of medicine was inevitable. Advances in science and technology and their impact on the practice of medicine pushed the humanistic skills of the healer further and further into the background. This myopic view of the application of the new medicine needed counterbalancing in order to preserve and protect the interests of those whose bodies and lives were affected by scientific medicine. While physicians took on the claimed objectivity and authority of science, the lay public embraced the political philosophical notions of liberal individualism and the accompanying legal rights. These rights asserted self-determination as a basic interest of liberty and led to the demand for the participation of patients in decisions regarding their own healthcare. That demand in turn led to growing legal support for what was considered a necessary element for patient participation in healthcare decisionmaking, the notion of informed consent. Thus, the concept of informed consent developed in the practice of healthcare and medicine as an integral part of moral reflections on the nature of medical treatment, patients' rights and the appropriate role of physicians.

As the Western world in the twentieth century witnessed the kinds of human denigration caused by immoral medical research conducted without restraint or respect for its subjects, attempts to control this kind of drive for knowledge were sought through several regulatory efforts. Although these regulations were publicly endorsed by the U. S. government and the AMA, the actual practices of medical researchers revealed a
blatant disregard for them. This research was not only conducted and supported by private interests but by governmental and public healthcare institutions as well. Revelations of these breeches in the conduct of ethical medical research further eroded public trust in the ability of the medical profession to regulate itself and in the authority of the professional role of physicians as experts in patient-physician interactions and decisions. However, additional legislative actions aimed at correcting imbalances in power between physicians and patients have had limited success in changing the attitudes and behaviors of physicians toward the self-determination decisions of patients.

Because of these failures by the medical profession to recognize, acknowledge and act on the importance of the patient-physician relationship beyond that of the beneficent and expert authority, the public responded through their Congressional representatives by appointing two federal commissions. These commissions were charged with the responsibility of studying the ethical dimensions of medicine and biomedical research for the protection of human subjects, and of assisting patients in asserting their moral and legal rights concerning their own healthcare. It was from these studies in the application of moral principles in the healthcare context that the principle of respect for the autonomy of others gained prominence over that of physician beneficence in healthcare decisionmaking. However, it was the codification of the philosophical concept of the autonomous individual, intended to free the hold of paternalism over patients in the use of medical treatment, that also served to further the distance and silence between patients and healthcare professionals. As discussed earlier, even the codification of the principle did not significantly change the attitudes and behaviors of physicians regarding self-
determination of patients. In fact, it served to move the focus of physicians away from the interdependence of relationship with the patient to the fulfillment of legal requirements and a duty of disclosure. Once again, the patient was, and remains, largely and essentially lost to medicine as particular and central in the relationship. Once again, the art of medicine remains elusive.
NOTES


3. Ibid., 67.


8. As quoted in Katz, 16; see also, Beauchamp and McCullough, 30-31.


15. As quoted in Pernick, 28-29.

16. Salgo v. Leland Stanford, Jr., University Board of Trustees, First District, Court of Appeals, Div. 1, California, (1957). In Key Fact number 12 of the decision, the court held that "A physician violates his duty to his patient and subjects himself to liability if he withholds any facts which are necessary to form the basis of an intelligent consent by the patient to a proposed treatment. Likewise, the physician may not minimize the known dangers of a procedure or operation in order to induce his patient's consent. At the same time, the physician must place the welfare of his patient above all else and this very fact places him in a position in which he sometimes must choose between two alternative courses of action. One is to explain to the patient every risk attendant upon any surgical procedure or operation not matter how remote...the other is to recognize that each patient presents a separate problem, that the patient's mental and emotional condition is important and in certain cases may be crucial, and that in discussing the element of risk a certain amount of discretion must be employed consistent with the full disclosure of facts...the physician has such discretion consistent, of course, with the full disclosure of facts necessary to an informed consent." (emphasis added).


20. Ibid.

21. Ibid., s.v. Declaration of Helsinki.
22. Ibid., s.v. American Medical Association, "Medical Guidelines for Clinical Investigation."


25. Ibid.

26. Ibid., 1236.


30. Cruzan v. Commissioner, Missouri Department of Health, 497 U. S. 261 (1990). Nancy Cruzan suffered irreversible brain damage following an auto accident, resulting in a condition of persistent vegetative state (PVS). Nancy's family petitioned the court on her behalf following over four years in PVS to seek permission to remove a feeding tube because they believed that Nancy herself would not have wanted to continue such measures under the conditions of her medical state. The legal battle took over three years, and ultimately had a significant role in the passage of the Patient Self-Determination Act (PSDA) of 1990. This federal legislation allows persons to make their wishes known regarding medical care, in advance, should they become incapable of doing so in the future.


33. "Principlism" is a term which denotes the characterization of the practice in bioethical theory of the use of moral principles, primarily those of autonomy,
beneficence, nonmaleficence, and justice, to address theoretical issues and resolve moral conflicts that arise in medical practice, including at the bedside. It has been the dominant approach in U.S. bioethical literature and texts. It has recently come under criticism from a variety of authors in bioethics literature. In general, most of the criticism is that principlism is too constrained a construct to sustain the large issues that bioethics and its "virtual rise to the status of orthodoxy," see Albert Jonsen's "Forward" in E. DuBose, et al., eds., A Matter of Principles? Ferment in U.S. Bioethics, (Valley Forge, PA: Trinity Press International, 1994).

34. Cassell, 54.
CHAPTER 3

AUTONOMY IN HEALTHCARE DECISIONMAKING:
A CONCEPTUAL ANALYSIS

Thus far it has been established that informed consent in medicine is a relatively recent phenomenon. Informed consent was not a major issue in medicine until the mid-twentieth century, even though earlier threads can be found. It has also been established that several external factors from both public and private sectors contributed to its emergence. Finally, it has been shown how dimensions of its meaning are based on philosophical and legal underpinnings.

Throughout the brief historical survey of U. S. medical ethics and informed consent presented in Chapter 2, the concept of respect for autonomy, understood as self-determination within the legal doctrine, emerged as the underlying ethical assumption of greatest importance. Because of this prominence, now paradigmatic in scope, the concept requires a closer examination as most prominently represented in contemporary moral philosophy generally, and U. S. bioethics literature specifically. The process is intended to provide an understanding of a definition of autonomy, including its assumptions, that has formed the basis of ethical considerations in healthcare decisionmaking in order to understand more fully how its impact in application has unintentionally resulted in the kinds of problems noted in Chapter 1.
The concept of respect for autonomy as a moral principle and as represented in contemporary U. S. bioethics literature has to do with a particular view of the self and is grounded in both political and philosophical theories. It is a notion that weaves together other concepts such as rights, duties, actions and personal freedom. The word autonomy is usually understood within a personal, non-political context as self-directed freedom, particularly moral independence. It is the most frequently mentioned moral principle in contemporary U. S. bioethics literature on informed consent. The concept of autonomy stems from a philosophical grounding in "the liberal Western tradition of the importance of individual freedom and choice" in both political and personal life.

The political and moral theory of American liberal individualism, founded to a great extent on the writings of Locke, Kant and Mill as noted in Chapter 2, views individual autonomy as a fundamental value and a basic right concerning individual freedoms. As stated in the Encyclopedia of Bioethics, "The basis for an action, social practice, or government policy to be [considered] right or good is in the values, practices or choices of autonomous persons." This view promotes the idea of autonomous persons as the ultimate source of a society's values.

Yet autonomy as an ultimate value and fundamental right is not undisputed and may be considered by some to be in conflict with other equally or more important values. For example, the autonomy of individuals may be viewed as in conflict or tension with a perspective of moral authority stemming from community or family-centered values: a view of complete disclosure to a patient regarding terminal illness as cruel and burdensome and therefore more appropriate for the family than for the patient; a spiritual
view of one's relationship to the Universe that shuns thinking or talking of bad things as
dangerous to the well-being of a person's harmonious existence in and relationship to the
Universe; or a view that a spouse's interests may at extreme times supersede the wishes of
the patient regarding death. All of these perspectives could be viewed as potentially
conflicting with a claim of primacy for individual autonomy. Similarly, in a healthcare
institutional setting, the autonomy of individual patients may be viewed as in conflict or
tension with other commonly held values of healthcare professionals, such the duty of
beneficence or that of justice.

Thus in developing an understanding of autonomy it must be understood that
autonomy as it is constructed and accepted in current U. S. bioethics and informed
consent laws represents a set of values inherent in its assumptions. Because autonomy is
a constructed view of the self, the values promoted by this construction are values which
are primarily personal and individual. These values are supported and promoted through
the application of the concept to a particular context, in this case, informed consent. But
it must be understood that these values represent one particular view, and are not
universally held or held as highly as they are in this view.

This chapter will examine the dimensions of a construction of autonomy that have
contributed to the development of informed consent as currently practiced. These
dimensions are both philosophical and legal. Although they can be separated in
explicating an understanding of autonomy, they are really intermingled in the
applications in terms of rights, duties, agency and actions.
Autonomy as Rights and Duties

The concept of autonomy as the foundation of informed consent in healthcare decisions is based in two different but mutually supportive frameworks, moral philosophy and law. Traditionally, individual autonomy from a moral philosophy perspective is grounded in "a principle of respect for [the] autonomy [of another] that focuses on the [individual] patient...who has a right to make an autonomous choice."^ Individual autonomy from a law perspective, on the other hand, is grounded in a duty of actions for one that directly corresponds to the right of the other. "Although the patient [has] a right to consent or refuse, the focus [in tort law] is on the physician who holds a duty and who risks liability by failure to fulfill the duty."^ Similarly, a distinction can be drawn between being autonomous, that is, possessing certain capacities which are understood to define an autonomous person, and being respected as autonomous. For one to respect another as autonomous is "to recognize with due appreciation that person's capacities and perspectives, including his or her right to hold certain views, to make certain choices, and to take certain actions based on personal values and beliefs."^ So if understood as a moral demand or rule for action to respect persons as autonomous beings, the concept can be restated in moral philosophical terms as a principle, that of respect for the autonomy of others. This moral principle or rule, then, provides the basis for the claims of individuals to the right to make autonomous decisions. Thus, from a moral right a correlative moral duty arises. As Faden and Beauchamp explain in A History and Theory of Informed Consent, "A right always entails the imposition of a duty on others either not to interfere or to provide something,
both the [moral] duty and the [moral] right being justified by the same overarching principle."

The right of privacy, considered the legal counterpart to the philosophical moral right of autonomy, can be understood in legal expression of the duty of respect for the self-determination of others. Although not explicitly stated in the Bill of Rights, the right of privacy is generally thought to arise out of the First, Ninth and Fourteenth Amendments. Law loosely relies in part on the moral philosophy of its society to delineate rights and duties, and from them legal liability, in both case and statutory law. Thus, a similar correlation of rights and duties appears in law as in moral philosophy. In the case of informed consent, the patient has the right to information and to make a personal choice, and the physician, primarily, has the correlative duty to give information and honor the patient’s choice. Consequently, the physician, and sometimes other healthcare professionals, may be held legally responsible (liable) for violating the patient’s right. This may occur either by failing to fulfill the duty of obtaining the patient’s consent, or by failing to provide adequate and relevant information in a manner understandable to the patient.7

**Autonomy as Agency and Actions**

In contemporary moral philosophy as found in much of the prominent bioethics literature, personal autonomy, or the autonomous self, is usually understood as personal self-governance or self-determination. This understanding or definition carries with it certain requirements necessary to meet the definition, such as "adequate understanding of
relevant information while remaining free from controlling interferences by others and from personal limitations that prevent choice. Thus, the autonomous self, as defined, entails possession of certain psychological capacities that usually include at least agency, independence, sometimes rationality, and various other capacities.

Moral agency is often understood as an awareness of oneself as having desires, intentions or plans, and acting on them so as to accomplish or satisfy them. It has been suggested that this capacity for agency is what distinguishes humans from non-humans. Non-humans may have desires, but lack "the capacity for self-consciousness that is manifest in having awareness of desires and their effect in actions." However, this is not to say that agency necessarily requires that one is never influenced by either internal (conscious or subconscious) or external forces or factors. Rather, it accounts for how persons are capable of acting through their own choice, not how they actually or always act.

Moral independence, also called voluntariness, can be understood as the absence of overwhelming or controlling influences on the moral agent. These are the kinds of influences that come as a result of external manipulation or coercion by others, and may directly and profoundly affect or alter a person's beliefs, life plans, values or actions. Within this understanding a person under such influences is believed to have little or no capacity to act autonomously. Moral independence, as understood here, also usually requires that a person have a range of options. Thus, as coercion and manipulation by others may work to defeat autonomy, so may social and physical environments or forces which artificially construct limits on a person's options for actions.
Moral rationality, rational decisionmaking or means-end rationality is a more controversial element of autonomy, depending on its definition and use. It is less controversial when understood simply as the capacity for reflecting on one's view of the good together with one's life plans to achieve the good. As such, rationality is choosing actions based on the best possibility for fulfillment of that view. It has been suggested that those who lack this capacity for rationality include those who are severely mentally ill, such as persons with schizophrenia or psychopathology. It might also include persons who are comatose, in persistent vegetative states or under extreme influence of drugs as when under anesthesia. Rationality as one of the necessary elements or required psychological capacities of autonomous persons is sometimes considered controversial because judgments of the rationality of the decisions of another are tied to beliefs and values. So there is a tendency to judge another's decisions or actions as rational or irrational in comparison to one's own beliefs or values, which are not necessarily those of the decisionmaker. Furthermore, it has been argued that both rationality and irrationality function within the normal as well as abnormal psychology of individuals, and so should not be viewed as either healthy or pathological respectively.

Personal autonomy or the autonomous self is often discussed in terms of describing a person (agent) and describing that person's actions. The autonomous person or self may be described as having the ability to reflect upon and adopt attitudes toward one's own view of the good and corresponding life plans regarding actions for the achievement of that view. For example, a person may choose to identify with their life desires, inclinations, values and preferences, or may instead choose to change them if they do not
reflect the kind of person one desires to be. This can be articulated another way as the concept of having the power of, or capacity for self-determination. Thus autonomous actions can be understood as those actions of a person that demonstrate the individual's overall capacity to reflect on one's value preferences, to alter them if desired at least in part because one has reflected on them, and then to make them effective through a course of deliberative actions. Gerald Dworkin has argued that "...exercising such capacity, we define our nature, give meaning and coherence to our lives, and take responsibility for the kind of person we are." Similarly, Stanley Benn has described an ideal of the autonomous person as,

the one...whose life has a consistency that derives from a coherent [self-chosen] set of beliefs, values, and principles, by which his actions are governed...The principles by which the autonomous man governs his life make his decisions consistent and intelligible to him as his own; for they constitute the personality he recognizes as the one he has made his own.  

Such descriptions conceive of an autonomous person as consistent, independent, resistant to control by others especially those in positions of authority over one, and the source of one's own choices regarding basic values, beliefs and actions.

Unfortunately, in contemporary moral philosophy and contemporary U. S. bioethics literature specifically, there is no universally agreed upon representation of the definitive characteristics of the autonomous person and autonomous actions. As previously noted and Faden and Beauchamp explain, "The capacity to act autonomously is distinct from acting autonomously, and possession of the capacity is no guarantee that an autonomous choice has been or will be made." For example, in healthcare informed consent, if a person fails to understand the relevant information given the choice made cannot be said
to be truly autonomous. However, that the choice is non-autonomous may have less to do with the person’s capacity for autonomous decisionmaking and more to do with the inadequacies of the disclosure of information. Thus within the context of autonomy as defined a person may be autonomous and therefore qualified to give informed consent, but the consent itself may not be a truly autonomous act due to various influences such as inadequate or poorly explained complex information, family pressures or other social responsibilities.

In contemporary moral philosophy there have been two dominant models of personal autonomy. The freedom model, that is, autonomy as personal freedom to act, focuses on describing the circumstances surrounding an action, including a decision or choice, and can be characterized by the writings of Immanuel Kant. In A History and Theory of Informed Consent, Faden and Beauchamp suggest a variation of the freedom model for informed consent in which there are three specific elements, or conditions, that define autonomous actions, including decisions. They suggest that a decision or choice is autonomous if and only if that action is done, "intentionally, with substantial understanding, and without [external] controlling influences." (This model does not include internal controlling influences, as others previously noted do.) In addition, they suggest that all three of these conditions are necessary for a decision (action) to be considered autonomous.

In this model, intentionality is not a variable or a matter of degree. An action is either intended or it is not intended. However, according to these authors the other two conditions, understanding and absence of external controlling influences, can be satisfied
to a greater or lesser degree. In this construction the concept of personal autonomy can be understood as if along a continuum from fully autonomous actions to fully nonautonomous actions, depending on the degree of satisfaction of the two variable conditions. This model allows for some actions to be considered substantially autonomous, although not fully autonomous, when there is a condition of substantial understanding but not complete understanding, and/or some controlling influence but not completely controlling influence. The threshold above which actions or decisions are treated as autonomous and below which are treated as nonautonomous is, the authors admit, a subjective interpretation. Likewise the term "substantial understanding" is also subject to interpretation and not further defined by the authors.

The fact that these terms are subjective and open to individual interpretation is problematic in terms of applicability of the model in the clinical setting by those who are usually charged with this responsibility but not trained in moral philosophy or medical ethics. Healthcare professionals, particularly physicians, are expected to assess the decisional capacity of patients whenever healthcare decisions need to be made. Yet most medical schools do not train physicians to make these kinds of assessments based on an understanding of moral philosophical concepts of informed consent and autonomous persons and actions. When decisions have significant outcomes at stake, such as potentially life-altering or life-threatening outcomes, the weight of the decision is viewed as greater and therefore the assessment more crucial. However, frequently the question regarding a patient's autonomous decisional capacity arises only when the patient's decision is not aligned with the medical point of view. When a patient refuses a
recommended medical treatment or procedure that is expected to have a significant beneficial outcome from the medical perspective, even if it has unavoidable risks attached, the patient's capacity is questioned even if that capacity had not been questioned previously. Healthcare professionals frequently assume that such a refusal must imply that the patient either does not have sufficient information, or does not sufficiently comprehend the relevant information disclosed. This is clearly a medically biased view.

Consider, for example, the case *In re Quackenbush*. Mr. Quackenbush was a 72 year old man who refused to have his gangrenous legs amputated. It was noted by his physicians that his conversation wandered occasionally, but not substantially greater than what might be expected as normal for his age. He had avoided seeking medical treatment for over forty years. He was neither in a terminal condition nor comatose. If he had the amputations he would live indefinitely, but not having the amputations would lead to his death. After examination by the judge the court determined that "the state's interest in preservation of life is not sufficiently compelling to override Mr. Quackenbush's right of privacy to decide competently his own future 'regardless of the absence of a dim prognosis.'" This determination supports that a prognostic indicator of outcome is insufficient reason to forcibly treat patients. Yet, as this case demonstrates, when a patient refuses a recommended procedure with a prognostic outcome viewed by medical bias as beneficial, the patient's decisional capacity is often judged by healthcare professionals as impaired. This kind of situation occurs frequently within healthcare institutions where patients are acutely ill or chronically dependent and at greater risk for abuse by medical power and authority.
Similarly, if a patient refuses a recommended treatment or procedure considered of significant benefit to the patient and decisional capacity is not in question, then external sources of manipulation become suspect. Healthcare professionals who observe a close relationship between the patient and another may view the relationship as manipulative or coercive if the perspective of the other person seems contrary to that of the proposed procedure and the other appears to have influence on the patient. This suspicion is the source of conflictual tension between a patient's significant other and professional staff.

Because the current model of informed consent is based on an individualistic view of persons rather than a relational view, the profile of the individual is the focus and others are added to that profile only tangentially. From this view others can only be seen as having potentially competing interests to those of the individual. This is precisely the starting point for the development of tensions between healthcare professionals and families as in the cases of Mrs. B and Mrs. M presented in Chapter 1. These tensions clearly arise out of the assumptions of the autonomy model of informed consent. But these assumptions regarding the autonomous individual, especially when threatened with illness, impairment or death, do not fit with intuitions regarding patients and their relations with close others. Furthermore, healthcare decisions often do have a dramatic impact on these others and it is remiss not to acknowledge the moral weight of their interests. Yet to merely recognize and acknowledge these interests is insufficient because in so doing the view of competing interests is sustained. The limitations of this autonomy model as the paradigm of informed consent regarding the influence and role of relational others in healthcare decisionmaking are made even more dramatic when
professional assessments are compromised by a lack of understanding concerning the complexities of relationships and their appropriate role in the decisions of individuals.

The suspicions of healthcare professionals are not necessarily completely wrong or improper and frequently are an appropriate source of discomfort that may trigger a closer interaction with the patient to determine unclear or subtle aspects of the patient's decisional process. But even closer interaction with the patient may only yield further doubt of the patient's capacities if done so from the perspective of medical bias inherent in the profession of medicine. Without a significant understanding of the intent of informed consent and its basis in moral philosophy applied to the medical context, medical professionals are likely to assess the variables of patients' capacities for understanding and amount of external influence at a threshold unrealistically high. These assessments are of particular importance when considered from the perspective of the unequal power within the relationship between professionals and patients. The intent of informed consent in healthcare decisionmaking is necessarily based on a dyadic, interdependent relationship between patient and professional; the professional possesses specialized knowledge essential to an informed choice, and the patient possesses the personal knowledge of self essential to appropriate use of medical treatment. Without this basic understanding and the appropriate skills for developing and nurturing their relationship, professionals on all levels and in all areas of expertise are not qualified to make the assessments for which they are responsible.

The authenticity model, that is, autonomy as "one's own" actions, beliefs, character and motivations, focuses on describing the person, and has been utilized by Gerald
Dworkin and Stanley Benn, as previously noted. A variation of the authenticity model of personal autonomy in healthcare decisionmaking was proposed by Jay Katz in 1984. He suggests that the contemporary debate over personal autonomy for a patient's self-determination and healthcare informed consent has been fought over two issues: rights versus capacities (agency). Katz defines autonomy not as a legal and moral right of autonomy or of self-determination, but as psychological autonomy which denotes the capacities (agency) of persons to exercise the right of self-determination. In other words, according to Katz, autonomy suggests a person's capacities to reflect about contemplated choices and to make decisions based on those reflections. Moreover, it emphasizes psychological and mental capacities rather than quasi-legal rights.

According to Katz personal autonomy or the autonomous self, defined in terms of psychological autonomy and its constraints, encompasses both conscious and unconscious motivations. It takes into account an ideational system within a person's psyche that can exercise motivating forces without being consciously accessed, and so must acknowledge and pay attention to the potential for conflict between conscious and unconscious motivations. Accordingly, all thoughts and actions are influenced by the simultaneous operation of conscious and unconscious forces with both rational and irrational components. Thus, in assessing the rationality of another's decisions, if assumed a necessary element in healthcare decisionmaking of autonomous persons, it is essential such assessment be based not only on an understanding of the patient's thinking in relation to his or her worldview and values, but also on a scrutiny by both health professional and patient of the significance to one's own view of the other's rationality.
Katz believes that in using this approach it may turn out that what is perceived to be an expression of a patient's irrational decision is actually based on different value preferences about the importance of longevity, quality of life, bodily invasions or risks worth taking. Furthermore, he cautions that rational and irrational should not be construed to mean healthy and pathological, respectively. Rather, he suggests they work hand in hand in both normal and abnormal psychological functioning of all humans. He argues that respect for another's personal autonomy or autonomous self, that is, the psychological or mental capacity to choose among options based on one's own values, beliefs and world view or view of the self, demands respectful, open conversation between health professional and patient that allows for personal perspectives which may appear irrational to someone with differing values and world view. Katz argues that the ultimate decision should belong to the patient who has to live with the decision.

The authenticity model has not gained the support and widespread use of the freedom model because it is more interactive, relational and conversational and relies on self-awareness and self-reflection of both professionals and patients, viewing their relationship as interdependent. Furthermore, it dismantles a simplistic notion of rationality and irrationality as oppositional indicators of mental health and decisional capacity. Thus, the authenticity model requires skills and knowledge that are not part of the scientific medical educational process and therefore uncomfortable to most healthcare professionals who are unfamiliar with them. It might also be more difficult to regulate this model. However, it is a model that is more closely aligned with the intent of the concept of informed consent as conceived in its philosophical grounding. It is also a
model that allows for a variety of considerations as legitimate in the process of healthcare
decisionmaking that would not be so in the freedom model. If it were more widely used
regulatory provisions and litigation cases might be less necessary. Therefore, the
authenticity model is more appropriate for affecting a condition of informed consent in
the healthcare context.

**Autonomy and Informed Consent**

The issue of informed consent is complex and involves ethics, law and cultural
influences. The concept in medical, legal, philosophical, regulatory and medical ethics
literature has been generally understood and defined in terms of certain elements
considered fundamental to that concept. These elements are primarily derived from the
dominant conceptions of autonomy as previously described in terms of capacities of the
agent (agency) and elements of the actions of the agent. Informed consent as commonly
understood in U. S. bioethics includes such notions as: knowledge and comprehension of
relevant information, reflection on one's choices regarding a decision to act (decide),
volutariness of action or the absence of internal and external controlling constraints,
ability to make a choice or decision, and making such a choice or decision known.²⁷
Various interpretations of this understanding generally agree on these elements as
necessary for a condition of informed consent, and differ only in which if not all of the
elements are necessary in any given situation.

This conception of informed consent has been criticized as a distortion based on
traditional medical conventions and authority, focused on the duty of disclosure of
relevant information and legal liability of professionals rather than on the meaning and intent of informed consent as an expression of a patient's autonomous decisionmaking. This criticism asserts that there is nothing in the nature of the concept of informed consent that necessarily requires disclosure of information as part of its meaning or as a necessary element in the analysis of its meaning. It is only in the interpretation of the concept from a particular view that the necessity of disclosure arises. For example, a person may possess information sufficient to make an autonomous decision without additional disclosure or a person may hold the view that to speak of potential risks creates them in reality. So, to require disclosure as a critical element without regard for the capacity or view of the particular agent is to misunderstand or misrepresent the intent of the concept from a medico-legal bias.

In considering the question, What is informed consent? at least two generally accepted meanings in medical ethics and the healthcare industry come to the fore. In one sense, based on philosophical underpinnings and prominent in bioethics, informed consent is understood as an autonomous decision or authorization (act) by a competent person. That is to say, it is a voluntary or freely chosen, substantially understood, intentional agreement to a proposed course of action.

In a second sense, based on legal underpinnings and prominent in the healthcare industry, an informed consent is understood in terms of, "...cultural and policy rules of consent that collectively form the social practice of informed consent in institutional contexts...[for the purposes of treating] groups of patients or subjects...." This definition is more that of an institutional consent which does not refer to any notion of autonomy.
but rather to a legal authorization by a patient or subject (as in research). This kind of
informed consent, the content of which can and does vary to some extent by state as well
as by institution, is not necessarily an autonomous act nor is it necessarily meaningful as
an authorization _per se_. It is, however, the mainstream understanding of informed
consent found in federal, state and institutional regulations of patient authorizations for
treatment. Its requirements do not focus on the autonomy of the agent or the act of giving
consent, but rather on "regulating the behavior of the consent-seeker and on establishing
_procedures and rules_ for the context of consent."30

This model is also the primary understanding of informed consent in the minds of
many healthcare professionals as disclosed in perhaps the largest national survey of
physicians' attitudes and understanding regarding informed consent. As noted earlier, the
results of this survey demonstrated that while physicians report seeking patient consent,
they have something quite different in mind than an autonomous act, or voluntary
informed choice by the patient. In their survey, the authors report that in answer to the
question "What does the term informed consent mean to you?" only 26% of the
physicians queried indicated that informed consent had anything to do with a patient
giving permission, consenting or agreeing to treatment; and a meager 9% indicated that it
involved the patient making a choice or stating a preference about treatment options.31

The overwhelming majority of these physicians appeared to recognize only the
information-giving component of informed consent, that is, the duty aspect of disclosure,
viewing informed consent as explaining the nature of the condition and treatment so that
the patient understands what is or will be taking place. To these physicians, informed
consent means only *telling* things to patients, not *asking* anything, such as permission. It seems that what is understood by many physicians about informed consent is that the patient's signature is required on a "consent" form after some kind of disclosure has been made, rather than any meaningful exercise of informed choice as an autonomous act by the patient. It would also seem that the legal underpinnings of informed consent in the duty of disclosure, rather than the philosophical underpinnings of respect for others' autonomy, has had a more substantial influence on the actual *practice* of informed consent in medicine.

These two constructions of informed consent, the philosophically based autonomous agent's act and the legally based requirement of a signature, are both understood in contemporary U. S. medical and biomedical ethics literature but provide a somewhat confusing picture of what informed consent is meant to be. The first model, based primarily in the philosophical understanding of autonomy, can fail to be informed consent as understood by the institutional or legal model, as for example if there is a lack of conformity to rules (e.g. the patient must be an adult or legally emancipated minor, must not be under the influence of mind-altering medications, must be legally competent to give consent, etc.) and requirements (disclosure must include risks and benefits a reasonable person would want to know). At the same time, the legal model of informed consent, based in regulatory provisions, similarly may not yield an informed consent as understood by the philosophical model, that is, an autonomous authorization for and agreement to a proposed procedure.

It has been argued, however, that these two constructions of informed consent need
not be mutually exclusive. They can be used together so that the first model becomes a condition, or a moral "benchmark," for the purpose of assessing the adequacy of informed consent framed for the institutional context. Thus, it may be argued that it is possible to align the social intention of informed consent, that is, enhancement of autonomous decisionmaking, with the legal requirements currently necessary within the institutional context.

Conclusions

This constructed understanding of autonomy and how it supports informed consent for healthcare decisionmaking is representative of the conventionally held view of autonomy, healthcare decisionmaking and informed consent that dominates contemporary U. S. medicine and medical ethics. The discussion has demonstrated that this conception of autonomy is rooted in philosophical traditions of liberal politics that highly value a kind of abstract individualism. The view of the self in this understanding is one of a solitary, independent, self-sufficient and self-actualizing individual. Its theoretical base favors a hierarchical ordering of various moral principles that give primacy to the principle of respect for others' autonomy. Its legal base is committed to personal liberty and the duty of others to respect that liberty.

The use of this conception as a model for informed consent has considerable limitations. For example, it requires an assessment of a patient's capacities for decisionmaking based on substantially subjective criteria such as understanding and influence by persons poorly prepared for that kind of assessment. This easily leads to a
subjective interpretation of another's decisions based on one's own values rather than on those of the decisionmaker. The imbalance of power and authority in the patient-physician relationship adds to the difficulty of an accurate assessment. The model only marginally recognizes interpersonal relationships and other types of social contexts, such as religious affiliations, ethnic traditions, or responsibilities to others insofar as these are viewed rather negatively, that is, as potential constraints, competing interests or controlling influences on an individual's autonomous acts. Furthermore, it misses the intention of informed consent, that of supporting the process of healthcare decisionmaking in order to enhance the autonomy of individuals' lives.

The conventional view has had a strong hold on the domain of U. S. bioethical theory, teaching and practice. It has served an important and useful purpose in early articulation of some of the difficult and conflicting issues at play within the context of increasingly complex medical science and technology. However, more recently this tradition is coming under considerable scrutiny, based on critical examination of its assumptions and the experience of clinical bioethicists in the trenches. It is becoming apparent that the role of autonomy in informed consent and healthcare decisionmaking as currently represented in U. S. bioethics literature may assume too much about the way many persons go about personal healthcare decisionmaking. It may also assume too little about the substantive role played by others in close relationship to the patient and the importance of other social contexts within which most humans live and die. As demonstrated by the examples in Chapter 1, it is becoming ever more apparent that the dominance of a notion of autonomy in healthcare decisionmaking may not be adequate...
for many individuals in our society whose world view may not value as highly the concept of individualism, or for whom relationship carries a more fundamental and influential role in their lives.
NOTES


3. Faden and Beauchamp, emphasis added, 4.

4. Ibid., emphasis added.

5. Ibid., emphasis added, 8.

6. Ibid., 7.

7. Ibid., 4.

8. Ibid., 8.


10. Ibid., emphasis added, 216.

11. Ibid.

12. Ibid.


14. Ibid.


16. Ibid., 71.


18. Faden and Beauchamp, 237.

19. Ibid.
20. Ibid., 238
21. Id.
24. There are several recent articles that address the inadequacy of the current model of informed consent, that of Faden and Beauchamp, by bringing forth the issue of families and relational others for legitimate inclusion in healthcare decisionmaking. To note a few: Hardwig; James Lindemann Nelson, "Taking Families Seriously," *Hastings Center Report* 22, no. 4 (July/August, 1992): 6-12; and Jeffrey Blustein, "The Family in Medical Decisionmaking." *Hastings Center Report* 23, no. 3 (May/June, 1993): 6-13. The notion that these considerations remain inadequate is developed by Mark Kuczewski, "Reconceiving the Family: The Process of Consent in Medical Decisionmaking," *Hastings Center Report* 26, no. 2 (March/April, 1996): 30-37.
27. Tom Beauchamp, "Informed Consent" in *Medical Ethics*, Robert Veatch, ed., (Boston, MA: Jones and Bartlett, 1989); see also, National Commission, "Applications." #1, 5-6; and, Faden and Beauchamp, chapter 8.
28. Ibid.
30. Faden and Beauchamp, 280.
32. Faden and Beauchamp, Chapter 8.
CHAPTER 4

CHALLENGING THE PARADIGM

Chapters 2 and 3 have outlined the development and subsequent defining of the prevailing approach to healthcare decisionmaking, particularly informed consent, in U. S. bioethics. The primary considerations have included: the development of informed consent as a legal requirement in healthcare decisionmaking; the prominent role of individual autonomy as a condition of informed consent; and the role of surrogates for individuals who do not possess those capacities, but who, nevertheless, retain the same rights. This approach has dominated both bioethics theory and practice in the U. S. for at least the past two decades. In fact, many healthcare professionals consider the principle of respect for autonomy as paradigmatic for their relationships and interactions with patients in healthcare decisionmaking situations. This is especially so with end of life issues, as demonstrated by the problems presented in Chapter 1.

The discussion thus far has been largely a representation of U. S. bioethics theory as found in most prominent texts and literature on the subject. It is a view that defines an ideal of the self as essentially solitary, independent, self-governing, self-actualizing, and free of controlling manipulation or constraint by others. This view focuses on rights and duties of individuals. It views others as largely outside the self-interest rights of the individual, and as having a duty to respect these same rights of all individuals. Thus.
within this framework two mutually supportive moral mandates emerge regarding the moral behavior of the individual toward others and vice versa. Moral consideration of the individual by others is expected to entail respect for the autonomy of the individual, and protection of that right on behalf of the individual who lacks the capacities for autonomy. Moral consideration of others by the individual is primarily viewed as interactions between equals, possessing the same rights as the individual and therefore deserving of the same respect for those rights.

Chapter 1, demonstrated a recognition of problems encountered in clinical contexts regarding this principle of respect for the autonomy of others in healthcare decisionmaking and the role of informed consent in supporting that principle. These problems are primarily due to a paradigmatic application of this autonomy model, not only as the philosophical base from which to consider approaches to bioethical problems, but also as a process for decisionmaking and the role of healthcare professionals in a context that serves individuals from a great variety of traditions, cultures, beliefs and value systems. In this application of a singular perspective to both the content and the process, the concept becomes too narrow and the process too confining. Thus, instead of respect for the autonomy of others being a point of liberating freedom to choose without paternalistic interference as intended, the perspective becomes limited by the constraints of its definition and legal requirements. In addition, the response to this singular model of definition and process by healthcare professionals has been to view their role of interaction with patients within the same constraints which further limits relationships and interactions between them. Thus despite the significant contribution of the field of
U.S. bioethics to the consideration, discussion and education of the public and professionals regarding ethical issues in medicine, the approach from a single perspective has also contributed to its limitations, subsequent problems and criticisms.

This realization has resulted in questions regarding the adequacy of this autonomy model and its view of the self and others as currently applied in healthcare and supported in U.S. bioethical theory. Challenges to the autonomy model have come from many different perspectives such as casuist, communitarian and utilitarian theories. The challenge for bioethical theory presented here is to demonstrate the need to include a process for consent and the role of healthcare professionals that is less constrained by definition and more open to interaction than the current model without abandoning the notion of autonomy altogether. This challenge is based in a relationship-centered care model constructed primarily from what is generally known as an ethics of care.

**Rights and Care**

It may be helpful to begin with a comparison between a rights or individual-centered perspective, and a care or relationship-centered perspective of morality and their respective constructions of the moral agent. In the rights or individual-centered model, individual autonomy plays a prominent role and has two main dimensions: moral autonomy and personal autonomy. Moral autonomy is a process of moral decisionmaking in a situation of conflicting rights. The moral agent uses skills of deductive reasoning, described as detached reasoning or logic rationality, to discern which in a set of assumed universally accepted moral principles ought to be followed in a
particular moral circumstance. Personal autonomy is a right, or entitlement, to freely pursue one's own visions of the good in one's own life and in one's own way. Moral autonomy stems from an ideal of the rational individual who, acting within a social contract model, upholds values found in a public market system. (Social contract theory will be discussed under "Claims of Universality" later in this chapter). Personal autonomy stems from an ideal of individual liberty in a political philosophy of liberal individualism. Together they form a view of the moral self based on autonomy rights that it is individual-centered. As such, the rights recognized support the individual as the moral authority over one's own life. At the same time, individuals are shielded from potentially intrusive moral demands of others and authority of the state which could infringe on an individual's pursuit of a personal view of a good life.

These rights and their corresponding duties to respect the same rights of others are designed to support freely choosing individuals in their liberty right to express their autonomous choices, so long as they do not unduly impinge on the rights of others, since 'the good' is accepted as a matter of personal interpretation. Therefore it can be understood that "rights secure for the individual an arena of personal liberty." Development of the moral self is marked by such characteristics as: independence, or separation from dependence on others; fairness, or public justice; and impartiality, or recognizing the claims and duties of others as equal to oneself. Moral conflicts arise within this understanding when rights of individuals conflict, or when one's moral duty conflicts with the rights of another.

A care or relationship-centered model of morality, on the other hand, is "an alternate
set of moral concerns where the central concern is a responsiveness to others that dictates providing care, preventing harm and maintaining relationships." In contrast to hierarchical ordering of moral values characteristic of the individual rights perspective and its primary positioning of respect for others' autonomy, Gilligan has described an ethics of care as based in a "network of connection, a web of relationships that is sustained by a process of communication." In this perspective, moral problems do not result from a conflict of rights between equals adjudicated by ranking assumed universally accepted values or moral principles. Rather, moral problems emerge from conflicting responsibilities within a specifically contextual framework of the relevant participants. Moral deliberations are "contextual and narrative rather than formal and abstract." Thus moral decisionmaking in a paradigm of care does not require a deductive reasoning process of weighing universal, competing principles and then applying the outcome to a particular situation and particular individuals. Rather, it requires a more fluid strategy that aims at maintaining and supporting relationships to the extent possible without sacrificing one's own integrity. In an ethics of care, personal integrity entails honest self-reflection regarding one's own needs, feelings and attitudes and taking responsibility for them by attending to them in relation to an ideal of caring for others. This perspective recognizes the interdependence of self and other, so that "the concept of identity expands to include the experience of interconnection." Within this perspective, the development of the moral self is characterized by an individual who freely chooses relationships with others based on caring attitudes, who has an increasing understanding and valuing of human relationships, and who strives to attend to the needs of relational
others while maintaining one's own integrity and caring for one's self.

A morality based in care and relationships has theoretical precedents in early Greek philosophy and other theories. Aristotle and Hume are predominantly the two who have been frequently cited as offering theoretical grounding for a care-based morality.

According to Aristotle, moral deliberations require cultivation of a moral character. This cultivation is the development of certain virtues and skills into habits that guide actions and interactions with others. These include discernment, deliberation, preservation of integrity, temperance, pursuit of excellence and maintaining relationships. This character development is on-going and occurs over a lifetime.

Aristotle taught that the capacity for moral judgment arises from the cultivated moral character and attends to circumstance, relevant individuals and context. Moral action is specific to the circumstances at hand and so requires details of a situation to determine the appropriate moral response. Thus, moral judgment does not rely on an abstract concept of the good, or on rule based reason. It has to do with much more than following or applying rules or doing one's duty. Aristotle taught that moral deliberation must determine the right thing to do at the right time, in the right place, to the right person and in the right way.

According to Aristotle, caring is a moral behavior that arises out of a desire to make the object of caring as good as possible. Moral actions of caring entail those aimed at the achievement of this good. However, there is no single definition of good. This is because perceptions of all things are based on the individual experience of being. So definitions of the good are contextual and determining moral actions must allow for
relevant contingencies that influence one's deliberations about those actions. Further, Aristotle stressed the social embeddedness of human beings and so the importance of sustaining relationships.

Hume asserted that the concept of morals implies a sentiment shared by all or nearly all human beings which allows for agreement on what is and is not acceptable in human interaction. Further, it implies a similar sentiment regarding actions and behaviors which cause general approval or disapproval in a society based on whether the actions are in accordance with or deviate from what is acceptable. These two sentiments are what Hume contended are required in defining human morality.

Hume's argument that morality is grounded in emotion and personal concern suggested that it is not rationality and reason that move us to act morally, but moral sentiments or feelings which arise in situations that motivate us to act and so guide moral life. This is not to say that reason plays no role in morality, but rather reason alone is not sufficient to produce moral judgment. According to Hume, reason is used in assessing the quality of an action's effects in what is good. But sentiments define those virtues and actions which are beneficial toward achieving the good. Hume also asserted that morality was a universal characteristic of all or nearly all human beings, and only if one rejected one's own human nature would one not share the experience of sentiments. He further argued that morality must serve not only the interests of the society but also the interests of the individuals in that society. Therefore general rules for what is acceptable must be open to exceptions in order to take into account relevant details of the circumstance. Thus practical wisdom for moral judgment takes into account both reason
and feelings. However, to Hume it is sentiments or feelings that are the greater necessity for motivating moral deliberations and actions. He also argued for the importance of and attention to relationships in considerations of appropriate moral actions.

For both Aristotle and Hume, then, morality is more than a set of rules agreed upon by all and applied deductively to individual situations. Morality thus accommodates general attitudes and behaviors of a society. But it also requires both the virtue of feelings or sentiments that motivate one to act in order to achieve a good, and the skill of reason in order to assess the quality of benefit in choosing a course of action. Morality supports a society by offering a sense of integrity, peace of mind and a satisfactory view of conduct which are the sources for human happiness. Although morality can be found in all human cultures, it must be contextual in order to pay due attention to the relevant details of a particular society's situation. This accounts for different views of morality in different cultures.

Central to a comparison between the perspectives of rights and care is their respective views of morality and the self. Morality from the view of individual rights and deductive reasoning begins with the self as a moral agent who is separate, independent from others, and self-sufficient. This independent self freely chooses the moral path to follow in situations of moral conflict, ideally grounded in assumed universally accepted principles governing moral actions. The moral choice will, optimally, infringe least on others' rights while maximizing self interests. By contrast, morality from the view of care and relationship begins with a view of the self as situated within a network of relations with others that is marked by connection and interdependence. This in turn leads to moral
deliberations which strive to maintain these relationships to the greatest extent possible.

From an individual rights perspective of morality, the primary injunctions for the moral self include noninterference, usually understood as respect for the rights of nonspecific others, and self-determination, usually understood as the pursuit of one's own perception of good in one's own freely chosen way. From a care perspective of morality, the primary injunctions for the moral self include giving care appropriate to a particular other in response to self-defined needs of that other, avoidance of harm by considering the self-defined harms of the particular other, and maintaining or supporting relationships, both one's own and those of the other, to the extent possible while maintaining one's own sense of integrity.

Claims of Universality: Self and Other

From the perspective of individual rights, abstract and universally applied principles for guiding moral interactions with others can be identified as the rights to live one's own life and to personal liberty to define that life, and the duties to respect the same rights of others and to keep promises. These principles are derived from a theory of a hypothetical social contract and are viewed as universally appropriate for all rational or potentially rational beings, i.e., all human beings. In a social contract theory interactions between individuals are governed by a model of behavior in which a group of people agree to a set of mutually acceptable principles of behavior to maintain social order. This concept relies on the assumption that rational individuals who have both common and opposing interests can agree to rules to arbitrate their disputes and facilitate their
cooperation. Current notions of this theory accept that the social contract is not actual, but rather hypothetical. Under this hypothetical agreement, rational people with the responsibility for deciding moral and political principles of a society would agree to include these principles for acceptable behavior under market or fair bargaining conditions. The idea of a social contract as a model for moral deliberations is to ensure the rationality and impartiality of the principles people elect for use in social interactions. While rational people would not agree to principles injurious to their own interests, neither could they expect others to agree to principles injurious to theirs. It is therefore just for individuals to comply with principles that are accepted by all under this agreement for mutually beneficial reasons.

From this standpoint, then, the governing principles can be articulated relatively easily as a formula, or algorithm, in which those on the receiving end of the action are viewed as variables that can be represented by virtually any individuals. When such universal principles are applied and the variable individuals are inserted in a given situation, an action imperative (principle) for the moral agent results. The reason for this is that the principles governing moral action are universally applied and do not change regardless of the individuals involved.

By contrast, the care perspective of morality does not usually accept such a deductive and universal application of abstract principles to particular situations and concrete persons. An injunction to give care in general can be considered essentially meaningless unless one first considers the different kinds of situations in which one may have a responsibility to care. From a rights perspective, too, it is important to consider
particular situations in order to determine what rights and duties people have. However,

Giving care further requires attuning oneself to the needs and desires [as they define them] that the recipients of the caring conduct have in a given situation. At this level, individuals must always be considered distinctive rather than typical, and decisions must be made responsively rather than deductively.\textsuperscript{13}

The distinction is that from a care perspective, unlike a rights perspective, the \textit{individual} that is the recipient of caring attention and action is of central importance in determining a moral action.

One challenge to the prevailing approach to healthcare decisionmaking and informed consent and its views of autonomy and the self, focus on individual rights, and principled approach to moral conflict resolution, is that it assumes a universality of what are claimed androgynous values. This assumption is predicated on a view of all individuals as essentially the same rational beings, and as such all having the same rights, duties and values in relation to other rational individuals. Benhabib has interpreted this standpoint in what she calls the 'generalized' other. She points out that in assuming this view,

We assume that the other, like ourselves, is a being who has concrete needs, desires, and affects, but what constitutes moral dignity is not what differentiates us from each other, but rather what we, as speaking and acting rational agents, have in common. Our relation to the other is governed by the norms of \textit{formal equality} and \textit{reciprocity}: each is entitled to expect and to assume from us what we can expect and assume from him or her. The norms of our interactions are primarily public and institutional ones.\textsuperscript{14}

Yet it can be argued that a rights perspective is far from androgynous, since it directly arises from experiences in the public context, that is, economic and political realms, and is grounded in a social contract model based on marketplace values.\textsuperscript{15} This perspective stereotypically reflects the social experiences and hence the values of men. Similarly, it can be argued that a care perspective arises from social experiences in the personal
context, that is, values of personal relationships and responsibilities of care in relation to family or close others. This perspective stereotypically reflects the experience and hence the values of women. This is not to suggest that either perspective accurately reflects an exclusive domain of the gender from whose experience it arises. Rather, it is more likely that the different perspectives reflect different experiences within society at large, and that those experiences generally align with gender. Individuals in both genders can and sometimes do share the perspective of the other. As Gilligan has pointed out, different ways of knowing based in different perspectives and experiences represent different ways of interpreting, valuing and viewing the self.  

Acknowledging these differing perspectives and the experiences that have given rise to them creates questions about what has been viewed as universal and androgynous. It is more likely that the autonomy model in bioethics has become dominant because it is the ideology of the dominant group rather than a universal truth. For example, Harding points out several significant parallels between the theories of feminine and African world views which she attributes to a mutual experience, that of oppression. According to Harding, there is a tendency for both to affirm the difference of their respective groups by distinguishing themselves from the dominating class of the white European males. Each group characterizes itself as being less interested in individual autonomy and much more concerned with relations to others and to nature than are white European males. Finally, both views are characterized by similar ontologies, epistemologies and moralities.

These similarities point to three notions that illuminate causal aspects of the
correlated dichotomies. First is the notion that "the feminine and African world views name what is absent in the thinking and social activities of men and Europeans, that is, what is relegated to 'others' to think, feel and do." Second is the notion that the increasing division of labor between the conceptionalizers and the executors through imperialism points to an additional aspect of the dichotomy of relationship between European and African labor on the one hand and male and female labor on the other. "For reasons originating in an analysis of social relations, we should expect white, bourgeois, European men to have cognitive styles and a world view that is different from the cognitive styles and world views of those whose daily activities permit the direction of social life by those men." As the struggles against imperialism and male dominance move forward, those engaged in those struggles are conceptualizing their own labor and experience counter to that of their oppressors. Thus, "we should expect differences in cognitive styles and world views from peoples engaged in different kinds of social activities. And we should expect similarities from peoples engaged in similar kinds of social activities." Third is the notion that developmental processes in infantile experiences play a fundamental role accounting for these cross-cultural differences. Despite developmental explanations for gendered world views that would seem to negate cross-cultural similarities, the work of Isaac Balbus provides some insight into this idea. His anthropological studies indicate it is likely that cultural variations in the intensity of infant identity with the caretaker and the severity of separation from that caretaker may provide an explanation for how the Western male "infantile experience leads to one set of
ontologies, ethics, and modes of knowledge seeking, while the infantile experience of the [females and African males] tends to produce a different set. From these insights, she suggests, one can see that a claim to the universality of liberal individualism, its rights and its values, begins to disintegrate.

Similarly, the theories that have dominated the U.S. bioethics domain concerning healthcare decisionmaking have given priority to issues of the public realm, such as individual rights, individual autonomy and duties based on rules of social contracts. This has in turn given priority to a view of others as abstract or generalized others. The other is understood as a generalized self, abstracted from specifics that form an individual's identity as unique, such as the nature of one's personal relationships, spiritual beliefs, ethnic traditions or socioeconomic status. It stems from an assumption of separation of the self from others and the need for an external structure of connection, a hypothetical agreement to moral principles universally applied to all rational beings.

In contrast is the notion of a 'concrete' other understood within the context of particular personal and cultural history. This view of the concrete other is a central moral standpoint in a caring paradigm. It stems from an assumption that individuals are essentially connected to others, such as families, culture and community. An underlying motivation of the caring moral agent is seeking an understanding of these particularities in order to maintain and support essential connections important to the individual's self-identity. Thus, the emphasis is placed on the active searching self rather than the passive acceptive self.
Self and Other in A Healthcare Setting

It may be argued that the moral imperative of care represents an ontology and epistemology for a coherent moral perspective that is particularly relevant to the delivery of healthcare in an institutional setting and as a moral ideal for healthcare professionals. For example, in the cases of Mrs. B and Mrs. M in Chapter 1, the healthcare professionals were primarily concerned with the interpretation of the autonomous rights of the patients. Their focus was on the fact that the patients had expressed certain desires regarding their last days of life. The spouses of the patients were viewed as peripheral to the patients and generally outside the realm of their concern. In a care paradigm the focus widens so that the patient is not only an individual person, but a person with a particular set of relationships, traditions and values that comprise the whole person. As such, the patient's connections to those aspects of one's self are brought into the focus. As Gilligan has observed, "The strength of the care perspective may lie in the refusal of detachment and depersonalization, and insistence on making [and keeping] connections that can lead to seeing the person in their particular context, and as a person in real relationship with others, as son, brother, father, etc."25

The two perspectives of rights and care offer different assumptions regarding self and others with differing views of human nature and the nature of the human condition. Their respective appropriateness in the healthcare setting needs to be determined. One of the main problems with the prevailing conceptions in U.S. bioethics literature and texts is that, in general, this view neglects the particularities that constitute moral predicaments typical of the healthcare setting. It has little to offer when those involved do not share the
values of individualism, autonomy and rights, or order these values differently from the dominant culture or view. Beliefs and values which exemplify these situations were presented in Chapter 1 including: beliefs that a spiritual force connects thoughts and words with a capacity to affect reality, traditions that view veracity regarding illness as burdensome and cruel to the patient and so more appropriate for the family to bear, and notions that the interests of a spouse may sometimes take precedence over assumed autonomous expressions of the patient. These views place a higher value on something other than the autonomous choices of individuals. The persons representative of these views were individual members of various communities, cultures and personal relationships that had profound, formational influences in their lives and views. Hence it seems clear that problems will emerge in healthcare from what has been assumed is a principle that is universally accepted and applied with patients in a healthcare institutional setting.

If one can accept that moral attitudes, values and corresponding behaviors arise within "the context of the particular lives of individuals that are embedded in particular sorts of relationships, then a theory of ethics should attend to the nature of the relationships that hold among those who are involved in situations requiring moral deliberations." Our experience of relations with others can include immediate and extended family, our community, spiritual beliefs or religious affiliations, social and economic factors, racial and ethnic heritage, gender and, doubtless, many more. If our sense of self is derived to a great extent from our experience of relations with others, then a conception of the autonomous self that does not give due consideration to these
interconnections between relevant others is likely grounded, at least in part, in an impoverished view of the self.\textsuperscript{27} Yet, a contractual view of the nature of human relations dominates current U. S. bioethical theory and practice and functions as a paradigm for relations between healthcare professionals and patients. This view of relationships has its centrality located in a particular conception of autonomous individuals, viewing those individuals as linked to their relationships, traditions and values only by voluntaristic social ties which can be opted out of if the individual chooses to do so. Beauchamp and Childress, prominent authors and leaders in bioethical theory and defenders of the primacy of respect for autonomous agents, have maintained that the prevailing notion of autonomy does not at all deny that community, traditions of culture or ethnicity, and relationships provide the grounding for moral development of the self.\textsuperscript{28} They further maintain that the prevailing view is vulnerable to objections by relationship-centered theories only in the insistence on the extent of respect due autonomous individuals. Thus they would seem to support such notions as a relationship between healthcare professionals and patients as appropriately based in a social contract model of rights, duties, impartiality and principles; a view of relations between individuals, including healthcare professionals, as primarily voluntary, and that this adequately captures the most salient moral features of such relationships; and a perception that this model also adequately captures aspects of individuals' traditions, cultures and social contingencies that are relevant to bioethical contexts, such as healthcare decisionmaking and informed consent.\textsuperscript{29}

Relationship-centered bioethical theory has argued that the prevailing view tends to
assume "an idealized image of the otherwise healthy [and autonomous] patient....[which]
arisest from a false conceptualization of individuals as capable of existing apart from any
social relationships....[and perpetuates a] mistaken vision of the isolated, self-sufficient
individual." This argument further suggests that the prevailing conception of an
autonomous agent "fosters a misleading ideal of the autonomous individual that
intensifies the already disadvantaged position of ...[many persons] within the healthcare
systems." The results of this distortion have had direct effects not only on patients but
also on those with whom they are in close relationship due to the construction of
standards for surrogate decisionmaking based on the autonomy model. Furthermore,"this contractual picture of human relations dominates bioethical theory and functions as
a paradigm for relations between providers and patients." 

This discussion directly applies to situations of surviving spouses presented as
exemplar cases in the first chapter. Both of these spouses were expected by the
healthcare professionals around them to step out of their specific relationships and
cultural traditions and acquiesce to assumed autonomous expressions of their spouses. In
both situations the surviving spouses stood to personally suffer significantly if they
followed the behavioral norms of substituted judgment and best interests standards for
surrogate decisionmaking. In both situations their relationships with the professional
staff deteriorated when they did not adhere to the expected norms of following the
assumed autonomous preferences of their spouses. In one of the situations where the
staff was highly technically oriented, the reactions of the staff to the spouse of the patient
may have even contributed further to her personal suffering. And in both situations the
staff tended to see the behavior of the spouses as something other than moral, either as a selfish motivation of personal preference or benefit or as irrational. Additionally, in the two empirical studies regarding cultural perspectives of traditional Navajo, Korean-Americans, Mexican-Americans and the legal mandates concerning informed consent of patients, the potential adverse effects on some members of distinctive cultural traditions were readily revealed.

Considerations In Healthcare: Professional Role Models

The question arising out of the preceding comparisons between the prevailing rights based individual-centered model in U. S. bioethics and a care based relationship-centered model is whether conceptions of the self, others and human relationships in their social contexts supported in the dominant model are appropriate for the healthcare setting. In answering this, it is important to first understand that how our view of the self influences what counts as voluntary actions. Second, our view about relationships between individuals and their social contexts will affect what may be considered available options for voluntary actions. Considering both of these in the context of the healthcare setting will affect a conception of an appropriate role model for healthcare professionals.

A rights-centered social contract model in healthcare decisionmaking has had a profound effect on how many healthcare professionals view their role in relation to patients and relevant others in a critical decisionmaking situation. Due at least in part to the paradigmatic application of this model and its legal mandates concerning informed consent, many professionals currently tend to focus on their role as patient advocate.
They further tend to interpret this as supporting the individual patient's right of self-determination and providing a voice for those who are not being duly heard. To an extent, this may be an accurate role interpretation. It will likely remain a congenial arrangement as long as the patient and close others agree to the expected norms of decisionmaking of this model based on fully informed consent, autonomously expressed preferences made by the patient and support of those preferences by relevant others.

However, in supporting these norms categorically as an understanding of the professional role in patient advocacy this model assumes that patients and their close others accept the values of liberal individualism and its conceptions of context-neutral generalized others. It also assumes that patients and their close others can freely choose to accept or reject specific elements of the traditions and social contexts from which they come and which have been internalized, embodied and have influenced their view of self. Yet, any individual's sense of self may or may not include such notions of others or available choices depending on the context of the individual's life. Social categories such as gender, race, class privilege, and cultural traditions affect psychological, physical and social experiences of every individual. In addition, where one finds oneself situated in human life will likely affect many of the opportunities available for individual choice. Thus, an argument can be made that what counts as knowledge of human life is to a large part derived from an individual's situated perspective. As a result, it is understood that these aspects of human life play an important role in shaping one's identity and attitudes concerning relationships with others, opportunities and choices for oneself. To the extent that these perspectives are directly relevant to patients in the healthcare setting, they have
direct bearing on the due considerations of healthcare professionals in their understanding of their role in relations with patients.

The very nature of the context of healthcare would seem to point to a need to reconsider an appropriate basis for healthcare professional roles. The highly personal, intimate, often life-altering and sometimes life-threatening nature of a healthcare institutional acute care setting does not seem to be an appropriate context for assimilation of marketplace values of a social contract model among equals. Some patients may largely maintain their usual autonomous (as understood in the prevailing definition) view and approach to their circumstances while under the stresses of illness, injury or other debilitating circumstances. Others, however, have never held that view or approach or are severely compromised by the circumstances. These individuals do not fit within the autonomy paradigm governing professional roles. When faced with this situation healthcare professionals often assume the patient's complete incapacity for decisionmaking and assume the professionals know what is best. Even when a surrogate is available for decisionmaking for patients, if the surrogate does not follow the autonomy model, healthcare professionals make the same assumptions. Thus the alternative for someone who does not or cannot fit within the paradigm is to be relegated to the role of subordinate or child and told what is best.

As a professional model for moral responsibility toward patients the prevailing view primarily recognizes the obligations of professionals to maintain and optimize the patient's or surrogate's capacities for autonomous choices. When autonomy is perceived as lacking or otherwise inhibited, the moral concern focuses on enhancing the potential
for autonomy to the extent possible so as to maximize that potential. This may be sufficient for those patients and their close others who choose a strongly autonomous approach to their decisionmaking while in a healthcare setting. It fails, however, to give sufficient role guidance for interactions with patients who do not fit the expected norms of this model and its values of liberal individualism. It fails to pay appropriate attention to distinctive aspects of individuals' lives which affect their particular view of self, relationships and human life. All of these issues have profound effects on healthcare decisionmaking and subsequent interactions between professionals and patients and therefore should be part of the considerations of healthcare professionals.

From the dominant view, professionals may assume that if the patient does not exhibit the expected norms of autonomy in healthcare decisionmaking, someone else must speak on behalf of the patient, and so a patient advocate is actively sought. In some situations, but not all, this may be appropriate. Unfortunately, this may easily result in some professionals assuming that those who do not exercise their autonomy rights are incapable of doing so, either due to some kind of manipulation or lack of the necessary capacities. It may also result in professionals assuming that the patient or surrogate does not or cannot understand the information and therefore additional information is likely needed. This may sometimes but not always be true. If the patient is known to not have decisional capacity and the surrogate is not conforming to expected norms in the specific situation, the professional staff may understand and accept the surrogate's reasoning, or they may accept a more sinister connotation of motivation, such as monetary benefits, inheritance or the like. Any of these assumptions may easily regress into a kind of
advocacy that is more like masked paternalism.

These assumptions can and do occur with some significant regularity, stemming from a professional focus on patient rights and the obligations of professionals to maintain and optimize those rights. Although not wholly wrong, it seems that what may be necessary is a somewhat different bioethical grounding as an appropriate model for healthcare professionals. Currently, patients or surrogates who do not embrace their autonomy rights in healthcare decisionmaking are viewed by many healthcare professionals as aberrant at best, incompetent or immoral at worst.

In considering an alternative perspective for the purpose of refocusing the moral concerns of healthcare professionals it will be necessary to change the lens in viewing these concerns. Based on the empirical research of Gilligan, such a shift from that of rights and the individual to that of care and connections changes the definition of what constitutes a moral problem and so leads to seeing the same situation in a different way. For example, a rights-based moral injunction for healthcare professionals is understood as maintaining and enhancing the individual patient's autonomy for healthcare decisions. This is not necessarily wrong moral motivation and behavior. However a care-based moral injunction might change the understanding to that of not turning away from relevant others in need. With this change in focus the professional's role and relationship with the patient changes to one concerning responsibility not only to the individual patient, but also close others who share an essential relationship with the patient and as such are deserving of caring attitude, attention and behavior. From this view, the healthcare professionals in Chapter 1 could consider their moral responsibilities to
include considerations of the needs of the spouses of the patients. From this view, the healthcare professional's role is one in which caring for the patient does not end with the patient but rather extends to include those who are relevant in the patient's life.

Additionally, healthcare professionals might shift their view of relationships between self and others. A rights perspective views as centrally important an individual free of controlling, manipulative influences of others. A care perspective views relationships as essential in the identity and survival of the individual. With this shift the focus changes to supporting the patient and important relationships to the extent possible as necessary connections that extend the patient's sense of self, beliefs and values in the world, in essence, the patient's self identity. The view of others changes from that of potential adversaries to that of a vital extension of the patient. Included in these necessary others are the healthcare professionals, putting their relationship with the patient within that vital extension as well. Viewing relationships with patients in this way requires a level of commitment that goes beyond respect and advocating for rights. The motivation for the professional is less one of protection of an individual's rights, viewing the patient as potentially in need of protection from others who could cause harm or claim conflicting rights. It is more one of an imperative for viewing the patient as a whole person who is in part defined by personal relationships and therefore the importance of understanding, maintaining and supporting those persons and relationships is stressed. From this perspective, the healthcare professionals could view their moral responsibilities as understanding the distinctive aspects of the relationships between Mr. and Mrs. B and between Mrs. M and her family. Understanding the distinctions which made the context
of their decisions clear could have formed the basis of a caring and less adversarial relationship between the spouses and the professionals. It can reasonably be assumed that caring relationships and interactions would be not only preferable but beneficial to the spouses rather than the added stress and discomfort created by an adversarial one. It can likewise be reasonably assumed that the patients, had they been able, would likely consider the caring, understanding and support of their spouses as beneficial to themselves as well.

Taking the previous example one step further, healthcare professionals could view their moral responsibilities as understanding the distinctiveness of their individual patients as whole persons. This would necessarily include understanding the importance and fundamental influences of culture, traditions, religious or spiritual beliefs and other life contexts on a person's self identity, and the expressions of values that may be evident in their approach to decisionmaking. In the studies of attitudes and beliefs regarding informed consent requirements outlined in Chapter 1, it was evident that healthcare professionals need to be aware of a potential threat to some patients' self identity by a uniform approach to information requirements for informed consent. In a caring approach to individual patients the professional begins from a recognition of the need in all persons to understand and be understood as a person. From that beginning, a focus on how to interact with this patient in order to maximize the potential for understanding motivates the professional's interactions. Skillful communication and engagement with the patient are necessary. If a grounding of understanding is to be established, consideration of the whole person, including the patient's perspective regarding
information, decisionmaking and relations with others is necessary.

These shifts in focus lead to a redefining of the self as a moral agent. An image of the individual patient as a solitary figure in focus against a background of others with competing claims and self-interests sees the individual as the center of consideration, easily removed from against this background. A change in this image sees the individual patient within, among and tied to others through relationships, together forming the foreground and background. As such, a web of relational human beings is in the center of considerations because the individual can only artificially be removed from the others. Within this perspective the professional self can be viewed as a moral agent who responds to the perception of need and who considers the patient as a whole. Furthermore, the professional moves from the stance of the passive advocate outside of and directive to the moral agent to an active participant in the relational whole. This view of the healthcare environment and the participants therein would necessarily include a holistic identity of self. The moral question for the agent changes from, What are the patient's rights and how do I support them? to, What are the needs of this patient and how do I respond? The skills required for this moral agent in consideration of moral actions include engagement or attuned listening, engrossment or interpretive efforts geared toward empathic understanding, active participation, and comfort with the unknown and dynamic future. These kinds of skills are not required in the paradigm of respect for rights and universal principles, and hence the danger of the new question being answered from a paternalistic view. They are required in the care model in order to assess the needs of the patient as the patient defines them and respond in ways that are meaningful and beneficial.
to the patient so that the patient recognizes them as such.

Which of the two models with their respective roles for healthcare professionals in relation to patients and healthcare decisionmaking within the context of healthcare is of central importance? Both perspectives, that of rights and that of care, can and have been argued as appropriate bases for moral interactions. However, if one accepts that a view of self, others, relationships and other life contingencies are socially situated and individually constructed, then a moral model that views these notions from a singular view may not be appropriate. It is conceivable that more than one view could be appropriate, even necessary, to allow for moral interactions among proximate strangers with differing views of the self, others, values, beliefs and traditions. Furthermore, oppressive pressures that affect decisionmaking may originate from multiple sources, including families, communities, socioeconomic status, gendered roles, cultural traditions and the hierarchical culture of healthcare in institutional settings. Finally, there may be aspects of both the autonomy model and the care model which could be appropriately applied.

In a search for a theory of bioethics that allows for the scope of diversity of individuals, with their richness of values, traditions and beliefs and that allows for professional roles which accommodate that diversity without compromising it, an autonomy model based on rights, individualism and agreement seems limited. This is particularly the case when considering the appropriate role of healthcare professionals. The autonomy model encompasses the values of liberal individualism that sustain this country's social ethics. Respect for the autonomy of others, grounded in the claim of a
universal right to self-determination, should function as a principle guiding policy and
law concerning informed consent. However, the process by which individuals exercise
their right and which informs the appropriate role of healthcare professionals in that
process needs additional considerations. A care model based on relatedness and
understanding seems to be better suited for these process considerations in the context of
a healthcare setting. A shift to the focus of a care model for appropriate moral concerns
of the healthcare professional's role with patients could alleviate some of the tensions and
conflictual situations that posit a professional in the role of protector of rights while
creating a potential for adversarial barriers with relevant others close to the patient. A
relation-centered professional role model could accommodate a complex of views,
values, beliefs and approaches to decisionmaking by considering the concreteness of the
individual patient as a whole person, not isolated from life contingencies but in part
defined by them. Such a professional role could accommodate, through skills of
understanding, a fully individuated autonomous person who values the right to make
personal choices according to self-chosen interests and values. It could equally
accommodate a person deeply connected to a multifaceted community of others who
would allow those others to make decisions for the patient based on what they determine
is best. It is not to say that the theoretical notion of autonomy cannot accommodate these
individuals. Rather, it is more that the current autonomy paradigm has been codified to
accept one specific view of decisionmaking through its requirements of informed consent
and the role of professionals tied to that view. What has resulted is an operationalized
theory of autonomy and its component model of informed consent, no longer understood
as a partial moral concern but as an absolute. Inclusion of care and connectedness at equal weight with rights and autonomy in the process of informed consent and the moral role of professionals would balance the theory of bioethics and open its discussions to the benefit of all.

Conclusions

One of the primary reasons that the prevailing model of autonomy for healthcare decisionmaking seems problematic as a moral grounding for relationships between healthcare professionals and patients is that its assumptions are grounded primarily in a social contract theory of the marketplace. This model supports such notions as a conceptualization of the self as autonomous, that is, detached and essentially free of dependence on others; a focus on rights and duties of equal individuals; and a universal, voluntary agreement on rules for adjudicating conflicts between individuals with little formal concern for other factors that are largely considered irrelevant contingencies. Its assumptions include that individuals ought to comply with principles for interactions that would be accepted by most individuals who do not want to sacrifice their own interests but are willing to compromise in order to obtain a mutually beneficial agreement between relevant participants. This rationale was important during the seventeenth century because it liberated individuals as their own moral agent from religious and political authorities. The social contract model certified individuals as moral authorities and obliged them to assume full responsibility for their moral beliefs and actions. The rights it recognizes equip persons to assert their moral and personal autonomy while protecting
them from unwanted interference. At the same time this model does not provide a morally appropriate way to respond to the limitations of its assumptions and its inherent bias toward liberal individualism as a universally accepted value. Acceptance and adherence to this model as an ideal for healthcare professionals in relation to specific patients under their care fails to adequately capture the intimate nature of a healthcare setting and its relationships.

It has been argued by Donchin that there is much to value in current conceptions of autonomy, such as its respect for others' voluntary decisionmaking, impartiality, and autonomy as a goal for personal development. She further argues that "reworking the conceptualizations of autonomy within medicine is more practical and thus preferable to rejecting it in toto."\textsuperscript{38} She contends that universality is the primary problem that would need to be abandoned. Further, she suggests a reconstruction of autonomy that integrates both the general and concrete perspectives, drawing on a plurality of perspectives for appropriate application in different contexts of human activity.

Meyers proposes a procedural view of the autonomous self.\textsuperscript{39} Her construction of autonomy is built on what she terms "autonomy competency" which includes various skills relating to the development of introspection, communication, reasoning, imagining and others that enable individuals to direct and control their lives in harmony with their true selves. Her account of autonomy seems to characterize what she considers the common struggle of individuals in resisting inclinations to conform automatically or less reflectively to social expectations.

Friedman has offered an account of personal autonomy which views the self as
primarily social. She suggests that autonomy is gained by experience with a variety of perspectives from which a person can assess choices regarding values. From this approach, an individual's life has value to that individual not only because it is one's own life, but because it is a life one has reason to value in part because one has been open to other perspectives and freely chosen personal values rather than simply unreflectively adhering to tradition. She contends that in contemporary society, especially in U.S. society, persons are more likely to be part of many communities. This multiplicity of value experiences can contribute to an individual's construction of self identity through choosing those that best meet with a particular view of an ideal.

All three of these reconstructions of autonomy hint at the possibilities for how a theory of autonomy could be enlarged to encompass the diversity of views of self, others, relationships and decisionmaking. In addition, they hint at how a reconceptualization of autonomy could be used to change the understanding of informed consent and the appropriate role of healthcare professionals. In this way, it may be possible to sustain the values of liberal individualism and autonomy while broadening the definition, interpretation and process of informed consent.

The healthcare culture and its institutions are a mirror reflection of the values and structures of U.S. society at large. Market values and the principles of social contract are evident in every aspect of contemporary life and interactions. As healthcare is marketized and patients are consumerized, the role of the healthcare professional has become depersonalized. Because of the very intimate nature of the healthcare setting, it seems appropriate to shift the focus of healthcare professionals to that which is amenable
to the context. The more fluid responses necessary in a care-based relationship-centered model provide professionals with a role that allows for particularizing patients and their needs. Further, it neutralizes the kinds of conflicts and potential adversarial positions of professionals in a rights based model characterized in the studies and cases at the beginning of this thesis. For these reasons, bioethical theory should be striving to incorporate the philosophical principle of autonomy and the process of care into a comprehensive notion of what is meant by autonomy, informed consent, and the appropriate role of professionals.
NOTES


5. Ibid., 19.

6. Ibid., 73-74, and 151-174; see also Women and Moral Theory, "Introduction," 7.


12. Ibid.

13. Ibid., emphasis added.


18. Ibid., 308.

19. Ibid., 310.

20. Id.

21. Ibid., 311.


23. Benhabib, 154-177, especially 163-167.


25. Ibid.


27. Donchin, 46.


29. Donchin, 46-47.

30. Ibid., 45.

31. Ibid., 46.

32. Ibid., 48.


35. Ibid., 23.

36. Donchin, 49.

38. Donchin, 50.


CHAPTER 5
REFRAMING AUTONOMY IN INFORMED CONSENT

Contemporary U. S. bioethics theory and practice emerged from the realization that the drive for new medical knowledge and the application of new technologies can proceed to the detriment of society and individuals almost as if with a will of its own. Informed consent as a necessary element of medical practice developed out of that realization and a concern for the ethical implications of research practices and applications of medicine on human subjects and patients.

The ethical foundation of informed consent lies in the promotion of two values: personal well-being and self-determination of individuals. In recent decades, various efforts have attempted to ensure that these values are respected and enhanced. However, informed consent as currently practiced has done little to effect these simple goals. Informed consent as it was intended remains a myth. It is instead a legalistic event designed to absolve medical professionals of their responsibilities to act in the best interests of their patients. The myth is further perpetuated by the promotion of a definition of autonomy that isolates patients not only from those who could help them to heal, but also those who have been closest to them. Thus autonomy as currently accepted for informed consent in most prominent bioethics theory can be considered a form of abandonment of patients by viewing them as autonomous and then removing them from
the context of others.

If the simple goals of personal well-being and self-determination of individual patients are to be reinstated as the goals of informed consent, autonomy as the overarching principle must be redefined in terms that go beyond the currently narrow content of capacities and actions. Similarly, the roles of healthcare professionals and families or close others must also be reconceptualized. Healthcare professionals must have a role beyond the assessment of capacities and the duty of providing information which includes expectations that enhance the process of patient decisionmaking and sustain important relationships. Families and close others must be included as essentially normative in the decisionmaking process of patients rather than as competing and conflicting interests. This redefinition of autonomy and reconceptualization of roles as a refocusing for bioethical theory and practice is the subject of this chapter.

In each of the preceding chapters, the focus has been on current U. S. bioethics theory and practice concerning healthcare decisionmaking and informed consent. Chapter 1 demonstrated that the legal requirements of informed consent directly conflict with beliefs, traditions and practices of certain groups of Americans. For example, Navajo beliefs preclude open discussions regarding possible future adverse outcomes and so advance directives and disclosure for informed consent are not only eschewed but viewed as potentially dangerous to the patient. Truthtelling and other such disclosures to patients are for certain Mexican-Americans and Korean-Americans viewed as cruel and burdensome, and so family members are considered those primarily responsible for decisionmaking rather than patients. In addition to issues of cultural traditions and
beliefs, the cases of Mrs. B and Mrs. M demonstrated that spouses of critically ill patients are faced with decisionmaking responsibilities that at times place them in direct conflict with the expectations and standards of surrogate decisionmaking norms. All of these problems result from the way in which healthcare decisionmaking, particularly informed consent, is constructed from a definition of autonomy and its codification in the legal requirements of informed consent.

Chapters 2 and 3 demonstrated how informed consent as the dominant legal and ethical framework for medical research and healthcare decisionmaking is grounded in a concept of autonomy as a view of the self and others based on rights, duties and liberal individualism. Chapter 4 discussed and contrasted an alternate view of the self based on a notion of the essential importance of relationships, interdependence and connectedness of all living beings. When considered in relation to the problems demonstrated in Chapter 1, these discussions reveal a need to enhance the quality of healthcare interactions, including the healthcare decisionmaking process, between patients, professionals and relevant others involved in that process.

This chapter will seek to provide an alternative approach to the limitations and problems found within the current paradigm. Based on the discussions of the preceding chapters, it is evident that any attempt to remedy this situation within the current bioethics framework must begin with an approach that seeks both to broaden the definition of autonomy for informed consent and to reconceptualize the roles of professionals in their interactions with patients and relevant others. Only through such a tandem approach will it be possible to effectively bring patients and professionals back
together in the intimacy at the bedside and merge the art of healing with the practice of contemporary scientific medicine within healthcare decisionmaking. To this end, this chapter will first focus on considerations for a redefinition of autonomy in order to broaden what is understood as an autonomous person with autonomous choices. This redefinition will have implications for healthcare decisionmaking and informed consent. Second, it will encompass a reconstruction of the appropriate role of healthcare professionals in interactions with patients and their families in the process of informed consent in order to support and enhance the new understanding of autonomy. Third, the cases presented at the beginning of this thesis will be reconsidered under the new framework.

**Autonomy Redefined**

Under the predominant definition in current U. S. bioethics, autonomy is understood to encompass two models of characteristics of individuals and their actions, the authenticity model and the freedom model. The characteristics that define autonomous individuals include independence understood as freedom from the controlling influences of others, self-governance understood as the ability to determine one's own values, beliefs and character, and self-actualization understood as the ability to make one's desires realized through a life plan of actions. These characteristics define the autonomous self as a person that is acting from the authentic self-motivation of that person outside of the substantial influence of others and thus is known as the authenticity model. The characteristics of circumstances that result in autonomous actions include intentionality
understood as an intended action, sufficient understanding of relevant information, and freedom from the controlling influence of others. Because the action is considered freely enacted by the agent, this is known as the freedom model. Within this conceptualization a person can be autonomous without necessarily acting autonomously. So autonomous persons and actions are assumed to be judged separately. Yet what counts as an autonomous person will affect what is considered an autonomous action. Thus they are closely related.

This current autonomy model in healthcare assumes the liberal right of individuals to self-determination, the most fundamental of liberal rights upheld in the U. S. Bill of Rights and supported in tort and statutory law. This right remains of primary importance in any conceptualization of autonomy and informed consent. However, the current definition is too narrow in scope regarding what counts as an autonomous person and autonomous actions and what governs moral interactions with others. What is necessary, then, is to broaden the scope of definition while preserving the importance of the right of self-determination.

The account of autonomous persons and actions predominant in the bioethics literature is a content specific account. This means that it proposes a set of criteria that persons or actions must meet in order to be considered autonomous, regardless of individuals' agreement with the criteria. This approach can be contrasted with that of an open account of autonomy that is based on the notion of individual management styles. It begins by assuming that individuals have a personal style for managing their own value systems throughout their lives. This style inherently expresses how one believes that one
should go about making choices, and in part causes the way one goes about making actual choices. Thus an individual's management style is revealed in the way one goes about making certain types of value choices, and it allows for persons to have different styles for different types of decisions. Having an individual management style for decisionmaking is essentially a way of approaching decisions that elucidates one's values, but it does not necessarily require conscious reflection on those values. Persons who are autonomous are aware on a conscious level that they have a personal management style, that is to say, they are aware that they make decisions in a particular way. But this does not mean that they must consciously evaluate that style. That specific choices result from an individual's management style for achieving the good is, however, a requirement of this autonomy account.

An open-ended account of autonomy has several advantages over the current content-specific accounts. First, a content-specific account makes autonomy the prerogative of just those persons who meet the criteria. There are doubtless many individuals who live and manage their lives according to their values that do not do so in a consciously self-reflective manner nor necessarily in accordance with other aspects of the criteria of liberal individualism. These individuals or their actions are frequently excluded from the current view. In addition, content specific accounts of autonomy for informed consent lead to the fragmentation of the notion, as in "autonomy 1" and "autonomy 2." Even if one accepts that autonomy is an ambiguous term and as such these are only partial accounts, in reality they do not capture the deepest intuitions of the notion of autonomy in various contexts of uses. In a pluralistic society an open account allows for what counts
as autonomous choices across a broad spectrum of values. By accepting a view that one is autonomous when one chooses according to one's subjectively preferred management style, this view embraces value pluralism. In contrast, in a content specific account, an individual who is believed to have mistaken values cannot have true freedom to choose and so interference may seem justified in order to make them more free. Thus, the individual management style of autonomy circumvents the problem of unwanted and unwarranted interference. This is not to say that interference is never warranted. Rather that interference based on the unilateral judgment of another's values as mistaken is unwarranted. Other justifications for interference may include protection of innocent others or protection of oneself.³

In considering this broader definition of autonomy, doubtless there are several areas of consideration that may make traditionalists uneasy. For this reason, two will be used here as examples of how this open account of autonomy can be further understood. First, in the content specific definition of autonomy, the tradition holds that reflection on one's choices is not just desirable but essential for autonomous decisions. This tradition stems from a view of hierarchical ordering of values and requires that if one is to act in order to effect one's higher-order values, one must reflect on one's lower order values or desires in that process. Likewise, some see critical evaluation of one's psychological states through the process of self-reflection as a process that liberates us from our base desires and makes us controllers of our lives rather than passive bodies through which our inner desires operate. Yet not all persons who are free and autonomous consider such reflection a requirement in their decisionmaking. There are free-spirited individualists
who prefer to act on impulse, as the moment arises, and who prefer to take life as it comes rather than contemplating the details and 'what ifs' of every decision to be made. Likewise, many prefer to live life on-the-edge, without the worry of potential but as yet unrealized outcomes. For these persons, the rationalist style of decisionmaking that weighs the pros and cons of all the options and then makes a decision based on the one option that is likely, but not known, to deliver the best outcome, is one that would seem burdensome at the very least. To force a rationalist style on these individuals would be disruptive and intrusive to their management styles and likely reduce rather than enhance their autonomy. Thus it can be argued that reflection is not really necessary for an account of autonomous decisionmaking.

Another area for consideration in the content-specific account of autonomy is the quality of the reasoning processes necessary for autonomous choices. In the predominant approach, if one is not able to make decisions based on deductive reasoning that satisfies a higher-order value or desire, one is usually considered incapable of autonomous decisionmaking. The less rational the process, the less autonomous the choice. This account requires that to be considered autonomous one must accept and proceed according to a rationalist process of deliberation. Yet there are those who are autonomous despite cognitive failings. The relevant determinant should instead be reflective of a person's individual management style, and whether the choices made are produced from that style. If a person makes decisions based on a management style, those decisions are more likely to be autonomous in the open definition of autonomy than are those made against or outside of that management style for that person. In this way,
thinking for oneself occurs when done in accordance with one's preferred style of managing one's life and choices, even if this seems outrageous or foolish to others.⁶

An open account of autonomy based in the assumption that autonomous individuals have a subjectively preferred management style for value choices that is not subject to many specifics may not be the most comprehensive answer to the task of broadening the concept of autonomy. Nonetheless, it is a good place to start. From this position, it is possible to discard what is too confining in the currently accepted definition to accommodate pluralistic values and widen the circle of what is acceptable.

In broadening the scope of autonomy the next consideration is what should be retained and/or discarded in the current predominant definition. The view of the self in the current definition is one who is independent and freely chooses one's own life ends without necessary regard to concrete circumstances or others as long as they do not impinge on others' rights. In this view of the self, others figure only as tangential contingencies that one may or may not choose to regard. This understanding of the self and others is limited if viewed from the perspective of those who do not see themselves as individuals isolated from others but rather as essentially and vitally in relations with others. It also is a view that is not consistent with most intuitions regarding relationships between most patients and families. This is particularly true when families are understood to include significant relationships to the patient that can be described in terms of closeness rather than biology.⁷ However, if the view of the self is that of one who is independent from others, then those who do not share that view are virtually excluded from the view. On the other hand, if the self is viewed as essentially in relations
with others either intimately and distantly, it does not necessarily exclude those who see
themselves as independent, solitary authors of their own lives and less in essential
relations with others. This second view is broader in that it accommodates both those
who view themselves as independent and those who view themselves as essentially
connected. It likewise allows for greater inclusion of others in the decisionmaking
process for those who view themselves as essentially connected with others or whose
traditions are such that the inclusion of others is normative.

Another point for reconsideration in the predominant view of the self is the claim of
universality of its values and application of rules. In the predominant view, others are
potential rivals to the interests of the self. It does not matter what the nature of the
relationship of these others is to the self because all others are self-interested and
therefore a potential threat to the individual. Therefore the principle of noninterference
with others and vice versa is of primary value. Principles for determining moral
interactions between individuals are intended to protect the individual's right of self-
determination and freedom from unwanted interference, and apply universally to all
persons. The individuals can change, but the rules do not. This view is problematic in
that the particular social situations of individuals and their relationships are not properly
taken into account. In so doing the view assumes that all individuals are equally situated
regarding the power within and the voluntariness of these relationships and the choices or
decisions they face. The claim of universality of both the value of individualism and the
rules that sustain it is a reflection of a social experience that is in fact not universal. It is
therefore necessary to reject this value in defining a broader view of the autonomous self.
This is not to say that the rights of individuals to assert their self-determination and view of personal well-being is to be rejected. Rather it is the claim of the universal value of individualism and the universal application of rules to sustain that claim regardless of the individuals that are rejected.

With this rejection of individualism the consideration of others in relation to the individual changes. The current view of the autonomous self and others sets up a dichotomy that pits individual interests against those of the family. This is not only a limited view in which close others are perceived as either threatening or nonthreatening interests, but also the source of potential antagonistic relations between the family and healthcare professionals who view their role as advocating specifically for the patient's rights. The entire schema is bound in the legalistic view of competing and conflicting rights and interests. By rejecting the universality of individualism and its rules for interactions the view of close others to the patient is allowed to widen. In this broader view, the role of family with the patient in healthcare decisionmaking is similarly allowed to widen, and the process of informed decisionmaking can take on a new dimension.

This is not to be misunderstood as sanctioning the abandonment of the importance of confidentiality between professional and patient. On the contrary, nothing in this account argued here would support such a breach of trust. Any effective therapeutic relationship requires a level of trust in interactions that requires maintaining confidentiality to the extent desired by the patient. Any discussion that included any other than the patient would require the consent of the patient and should never be assumed.

In returning to the goals of informed consent as outlined by the President's
Commission, that of enhancing personal well-being and self-determination, it is possible to understand how the current model of informed consent has missed the point of its intention. By relying on a model of autonomy that supports a legalistic view of interactions between individuals focusing on rights, the intended goals of informed consent are lost to bioethics discussions. Instead, the goal has become that of sustaining a particular view of what is required to secure the right of self-determination and bioethics discussions are necessarily centered on or around that right. Broadening the view of autonomy as demonstrated opens the discussions so that informed consent can be reclaimed as the process it was intended to be and its goals reinstated as its proper focus.

The redefinition of autonomy as discussed moves in this direction. First, it begins with a notion of autonomy that is not bound to content-specific requirements for autonomy to be satisfied by individuals. Rather it opens the notion in the sense that the self-determination of autonomous persons is reflected in their decisionmaking when those decisions are consistent with a subjectively preferred individual management style. Second, the redefined view of the autonomous self is a self that is understood as essentially in relation with others, both intimately and distantly. In this way, decisions made by those who consider themselves essentially connected to others, who may even acquiesce to the authority of others for the purposes of personal healthcare decisionmaking, are considered essentially autonomous decisions. Although there is a danger that some individuals may be coerced into decisions by others, it is not the starting point for considerations. Rather, coercion is suspected only when there is sufficient indications of its presence. Finally, the redefined notion of autonomy rejects the claim of
universality regarding the value of individualism and the supporting rules governing interactions between individuals. With this rejection, the singular view of others as the source of competing rights and self-interests is rejected and replaced by a view of close others as a normative extension of the interests of the patient. Together these form a notion of autonomy that is more open in interpretation and more inclusive of those persons and actions that heretofore have been left out of considerations of what it means to be autonomous.

**Reconceiving Informed Consent, Family and Professionals**

In current U. S. bioethics discussions concerning informed consent, the primary question regarding patients and families has been, Whose interests should take precedence in healthcare decisionmaking when the interests of the patient and family conflict? This is a result of the legalistic rights orientation of the definition of autonomy, a focus on self-determination and a conception of informed consent as an event. But with the redefinition of autonomy and refocus on the patient's well-being in addition to self-determination, the question can be reframed as, What are the respective roles of the patient, family and healthcare professionals in enhancing healthcare decisionmaking and informed consent? This redirection of informed consent to the intended goals arises from the understanding that informed consent is not only the event of making a decision at a moment in time and signing a form. In addition and more significantly, it is a complex process involving not only the individual, but for the majority of persons close others as well.
A transformed notion of informed consent arising from the broader definition of autonomy begins from this view of decisionmaking as a process. In this process model, the patient, family and healthcare practitioner, usually the physician, have access to facts and values that have interrelated significance and evolve with discussion and over time. The aim of the interaction is to determine the best health-related values for the patient that can be realized in the clinical situation. Through discussion, the patient's health-related values are open to development, examination and revision. In addition, other moral values not specifically health-related may be elucidated to directly or indirectly impact the viable options. Thus, the goals of well-being and self-determination of the person are brought into conscious focus.

In most bioethics discussions regarding the role of family and healthcare professionals in informed consent, the view has been that when there is no significant or unresolvable conflict, the family assists the patient in decisionmaking whose autonomy is generally seen as diminished due to illness or injury. The role of healthcare professionals involves the disclosure of information to the patient and family. They primarily provide the details of options, likely risks and benefits and answers to questions by the patient and family. These roles flow from the view of the patient as an essentially cognitive and rational being who holds clearly discernable values which are easily articulated in decisions regarding healthcare options once the relevant information is known and understood. Consent becomes the event that takes place once the disclosure is made and the information understood. In this view, the roles of the family and healthcare professionals are largely peripheral to the patient's cogent and personal decisionmaking.
When the patient's decisionmaking capacity is severely impaired, the roles of relevant others consists in deciding the way the patient would have decided if preferences are known or, if not known, deciding how the patient would likely have decided. These roles are inadequate when considered in view of the redefined notion of autonomy and informed consent.

The importance of shared decisionmaking is included in the President's Commission's articulation of the process of informed consent. The sharing implies a division of labor, so to speak, in which the practitioner labors over the available facts of the situation and options to be considered and the patient labors over the impact different options may have on personal life values. When the two are brought together the resulting decision more closely reflects the effort and perception of enhancing the patient's personal well-being for both practitioner and patient. In addition, unconscious influences often play into how and why a person makes a particular decision and may become more apparent through discussion in which the aim of well-being is prominent. Finally, since well-being is more than just physical and for many individuals difficult to elucidate, most patients will significantly benefit from the active involvement of close others in the decisionmaking process. This involvement in the process as normative further serves to diminish the psychological isolation of the patient, particularly in the institutional setting. Thus it becomes obvious that in aiming to achieve the intended goals of informed consent, the process requires the essential involvement of close others to the patient who may contribute to the enhancement of the patient's sense and definition of well-being and bring to the foreground values, insights and intuitions that may remain otherwise hidden.
In a reconstructed model of informed consent, although reflective deliberation is not required, it is highly desirable. Few other decisions in one's life can have such an intimate, life-altering and often irreversible impact as those regarding potential risks and benefits of various treatment options. Yet deliberation if done at all need not be done alone to be considered expression of self-determination or consistent with one's conception of well-being. Involvement of those close to oneself is beneficial in supporting the individual and contributing to the considerations of values or factors possibly overlooked, forgotten or not previously considered. In addition, in order to verify and clarify which of fleeting or vacillating expressions of choices under stressful circumstances disclose underlying values, the input of others who know the patient well and can place these in larger context is necessary. Thus the role of family takes on essential dimensions of both interpretation and deliberation in the process of informed consent. This expanded role as normative starts from an assumption of trust that is foreign in the current model.

Similarly, disclosure of information by professionals need not be limited to the recitation of facts and figures concerning potential risks, benefits, likely outcomes and alternatives. It should include the integration of medical information with the relevant values of the patient to formulate a coherent recommendation that takes both into full account. Further, to expect that patients enter new situations facing new possibilities with a coherent and well developed set of values to guide choices is not reasonable. To the contrary, "the patient gains new appreciation for various treatments as she accumulates experiential knowledge from undergoing them. This continuous refinement of
knowledge and development of preferences [in relation to values] are important aspects of process approaches to consent." Thus the process involves both clarification and development of personal values with others close to the patient. The role of the healthcare professional in this process is in elucidating the health-related values inherent in the different treatment options as they relate to the values of patient. It will necessarily require collaborative interaction not only with the patient but with the family as well, particularly if the condition is chronic or treatment is on-going. This kind of interaction between professional and patient/family also requires a fundamental mutual trust and respect.

In the redefined notion of autonomy and informed consent, the family is considered an extension of the interests of the patient and as such an essential and important part of the decisionmaking process. Just as it is unlikely that patients arrive with fully developed, consciously accessible values regarding medical treatment options, it is just as unlikely for their families. And just as patients undergo a process of clarification and development of values concerning the impact of their choices, so do families. These are not just parallel processes but also the same process taking place in an interactive and interrelated way. It may be that long-held values are adapted to new treatment and illness situations, or it may be a fundamental reordering of values incorporating new and previously unknown values. Either way, informed consent is a process of mutual self-discovery that often redefines the individuals as well as the family as a whole. Essentially, "In the process of decisionmaking, the context is also dynamic." 

With this understanding of informed consent, values clarification or development and

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the role of the family, the interaction and relationship between professionals and family should more closely mirror that between professional and patient. In the process model of informed consent, the assumption is that values are not the private, privileged property of the individual. Rather, "They take shape publicly, and when they are opaque or absent their discovery or construction is also a communal process." The role of healthcare professionals in this process is one of advocating for health-related values. This does not mean advocating any and all treatment available as valuable in and of itself. Rather, it means to advocate for those treatments that are clearly beneficial to generally accepted notions of health and well-being, and with limited risks. If the benefits are not so clear or if the risks are high, then advocacy should recede. When the patient's and/or family's refusal of a clearly high benefit/low risk treatment is consistent with stable long-held values, the advocacy also should recede. If it is not, then advocacy for treatment should proceed until the situation or the consistency changes. Caution must be taken, however, so that advocacy does not proceed to coercion.

The role for professionals is not only as advocate for those treatment options that will support the patient's values. It is also as advocate to support and maintain the relationships that are important to the patient's sense of well-being and self as a person. It is in this advocacy that the skills of communication, discernment, engagement and engrossment are critical for the development of professionals skilled at the art of healing. The art requires not only the knowledge and use of the tools of the profession, but also the skills necessary to know the patient in order to know how to act in the patient's best interest. It is obvious that to know the patient in this way professionals must understand
the patient's sense of self which for most entails their close relationships. Thus a professional cannot consider a therapeutic healing relationship with a patient without also considering a similar relationship with others who are part of the patient's self-definition. In this way, relationships are interconnected, essential and part of the professionals art of healing.

In summary, the roles of family and professionals in interactions with patients throughout the process of decisionmaking is significant. In this new model of informed consent, the legal requirement can remain an event but it retains far less significance in the overall process.

**Informed Consent In Practice**

At the beginning of this thesis, the problems encountered in the current framework of autonomy and informed consent in healthcare decisionmaking were illustrated by traditional Navajo spiritual beliefs affecting direct truthtelling about illness and outcomes, Asian-American and Mexican-American cultural notions of self and others in the context of illness, and the cases of Mrs. B and Mrs. M in the position of family faced with critical decisions under constructed behavioral expectations resulting from standards for surrogate decisionmaking. Within a redefined notion of autonomy and informed consent and the reconceived roles of family and healthcare professionals, there exists the potential for a new approach to these situations. From within this model, the situations of decisionmaking and informed consent presented in Chapter 1 will take on a different configuration.
Professionals educated about in this redefined notion of autonomy and proficient in the process model of informed consent will be aware of and open to the diversity of values concerning decisionmaking and notions of consent. Professionals would expect that individuals of all ethnic and cultural backgrounds have traditional beliefs and practices that shape those values and practices. The basic understanding would entail that within groups, some follow traditional ways and others do not. The approach is one in which each patient is treated as unique. So the need for the professional is to develop a relationship with each patient that allows for important exchange of knowledge concerning the patient's preferences about healthcare decisionmaking. Further, professionals must understand that individuals make value decisions based on a style of decisionmaking that is comfortable to that person. Such decisionmaking styles do not always follow a pattern of conscious self-reflection and may appear to be irrational or at least superficial. Some patients' traditions may include notions of the family or elders as the appropriate persons for directed disclosure and decisionmaking. Under a more open understanding of autonomy and self-determination, these would all be considered potentially autonomous actions that may be revealed through skillful communication and interaction.

For a practitioner in a Navajo tribe with patients who follow the traditional ways, the focus on enhancing well-being and self-determination of the individual patient comes with a basic understanding of the traditional view of the self in essential interaction with the Universe. Cause and effect beliefs are part of this understanding. Based on this knowledge, understanding and communication with others in the community such as
tribal leaders, council members or others in similar tribal communities will lead to a way for respecting traditional beliefs while accomplishing the global intent of policies concerning informed consent. This could take the form of discussing risks and benefits or advance care planning in terms of a fictional third party. Instead of discussing prognosis or the like in terms direct to the patient, the discussion could be conducted in a series of questions such as, If you knew a tribal member such as yourself who had an incurable illness, do you think that he or she would want to undergo chemotherapy if it might prolong their life? Do you think that he or she would want chemotherapy if it meant there might be significant side-effects? Do you think that he or she would want to have surgery if it was likely that the surgery could relieve pain but there's a chance of paralysis too? And so on. This type of approach could provide for a meaningful interaction that may elucidate the personal perspective about important treatment options while maintaining the integrity of the patient's belief system with due respect.

The legal requirements of disclosure for informed consent become secondary. Although such legal considerations as consent forms are unlikely to disappear, they do not necessarily have to remain in their present form, or they may be opted out of for those who do not believe in them. For example, if consent forms remained necessary for the fulfillment of legal requirements, they could be revised to allow for the acknowledgement of a discussion concerning potential risks, benefits, options and so on without being directly about the patient. Discussion concerning these kinds of efforts with tribal leaders would yield far more satisfactory solutions and approaches based on the deepest knowledge of their beliefs than is possible here. The point is that consent forms would
not be the focus of care nor the foundation for an interventional approach to healthcare decisionmaking.

Similarly, for practitioners who work in predominantly Mexican-American or Asian-American communities the expectation that some may hold the traditional views of truth-telling in illness should be understood. Developing relationships with individual patients would include knowledge of or familiarity with close others as an extension of the patient. Instead of assuming that patients wanted and should be told everything about their illness and their options, the assumption would be that this is not normative in many populations and so should proceed with perceptive awareness and careful interaction. For patients who view family or elders as the appropriate ones to receive information and make decisions for the patient, the interactions with family would not be considered aberrant but normative.

The diversity in values, beliefs, perspectives, traditions, cultures, and ways of living and knowing is itself understood and valued to the extent that practitioners must view them not as exceptions or divergences to work around, but as integral to humanity and so to be supported and preserved to the extent possible. Professionals in ethnic communities who practiced from a such a model of autonomy and informed consent must be familiar with and understand individual patients and their values sufficiently to integrate those values, with the patient's agreement and participation, in developing treatment plans that fit the context of the patient's life and sense of self. In this way, the process preserves the patient's integrity as part of the goal of maximizing the patient's life potential through enhancing well-being and self-determination as patients themselves define them.
Unless the legal requirements of informed consent are changed in a way that alleviates the necessity of disclosure, not a likely event, the legal aspects will have to be dealt with in a manner that allows for those who do not view direct disclosure as beneficial to the patient. In the mean time, once professionals are able to discard the previous notions of autonomy and informed consent for the broader views and process models, the goals of enhancing well-being and self-determination can readily embrace a variety of traditions and beliefs that include limitations on truthtelling and a more extensive involvement of family and others. Attention must be paid to signs of coercion or abuse by those in positions of power, but this should not be the starting point of relationships with families. Rather, trust should be the basis of the interactions and should only be questioned when there are signs to the contrary.

Interactions with surrogates will also be improved. Current standards of surrogate decisionmaking support the individualistic model of autonomy. Expectations regarding the decisions of surrogates based on this model often put them in direct conflict with other legitimate concerns and interests. In the case of Mrs. B who was faced with the responsibility of agreement with treatment limitations that would directly lead to her husband’s death, the healthcare professionals expected her to sign the consent in agreement. Although they understood that she did not want to lose her husband in death, the expectation remained as a result of their understanding of their role as patient advocate. This narrow view of their role left them with little other choice for appropriate interactions with Mrs. B, particularly after the patient’s expression of readiness to die. With a broadened understanding of autonomy that includes a view of the self as

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essentially connected to others, a self that is in part defined by one's relationships to others, the advocacy role of healthcare professionals necessarily includes extension of that role to others close to the patient. From this view, the interactions with Mrs. B must not be adversarial but rather must take on the caring attitudes and behaviors that are an extension of those with the patient. This view of others is critical from the perspective of a broader conception of autonomy. To assume that close others are somehow transformed into rivals of the patient once they enter the healthcare system is not only contrary to the intuitions and experiences of most persons, but ludicrous as well. Although there are instances where family or others may not reflect the patient's perspective nor choice, this should not be the starting assumption for interactions with family or others but rather surface only when there are indications for it.

The Nevada Statute requiring the written consent of surrogates for treatment limitations that may result in death was, in part, designed to protect individuals who do not have an advance directive and who are facing a prolonged process of dying perhaps against their wishes. The good intentions aside, this statute has instead resulted in forcing countless surrogates to participate in what amounts to a legal absolution of responsibility for professionals and institutions. It effectively magnifies the emotional trauma that these painful decisions normally entail without the intrusion and distrust of a signed consent. Such legal requirements as this only serve to perpetuate the notions of others as adversaries, both of the patient and of healthcare professionals, and so should be repealed or at least not required.

In the case with Mrs. M, several issues will be alleviated by approaching the situation
from the alternative perspective. First of course is the view of others as an extension of the patient. Mrs. M and the patient had been married for many years. They had shared cultural traditions from their birthplace that they had continued in their new life in America. Even with the understanding that many marriages are not ideal regarding the relations between wife and husband, nonetheless any long-term relationship remains for some reason of connection, healthy or otherwise. Unless there is significant reason to the contrary, healthcare professionals must approach significant others from the perspective that these others are important to the patient, an extension of the patient's identity, and have contributed to the whole of the patient's experiences of life. From this essential understanding, professionals must take into account close others and all relevant information such as cultural or religious traditions or beliefs as part of the patient's value system and existential meaning of life. In this, family and close others remain inside the circle of relationship with the patient and professional, instead of peripheral to it.

From within this circle of relationship, the healthcare professional's interactions must seek to gain understanding of the particularities of the those in the circle. In the case of Mrs. M, this would include the importance of the role of her sons in decisionmaking that places her in a subservient role. As difficult as this is to accept for many in the Western liberal cultures, it is not particularly unusual for the adult sons to figure prominently in other cultures, particularly Eastern, Middle Eastern and Mediterranean. For Mrs. M to eschew the decisions of her sons would have meant her own abandonment and estrangement from family.

In this particular situation, the healthcare professionals must first have this
understanding and second base their interactions with Mrs. M on this understanding in
the absence of a directive by Mr. M to the contrary. To presume that their role was
strictly that of advocating for what Mr. M presumably would have preferred is to neglect
the needs of Mrs. M and her role as essentially connected to Mr. M. This does not mean
that healthcare professionals must necessarily agree with such traditions or accept them
unquestioningly. It is appropriate for interactions by professionals to include attempts at
persuasion for a particular course of action that reflects certain health-related values. In
this case the staff would strongly advocate for treatment limitation with the sons, urging
them to consider that their father would prefer to die at home. In addition, nothing in this
approach requires healthcare professionals to provide treatment that is contrary to good
medical practice. For example, if it is against medical standards of practice to do CPR on
a patient with end-stage cancer, and it is, then it would be appropriate to not initiate such
treatment or procedure. It places appropriate responsibility on the professionals to make
determinations regarding treatment indications and to refrain from offering inappropriate
treatment. For Mrs M, this approach would have removed the burden of knowing that
she could not effectuate her husband's preferences without serious detriment to herself.
This approach would not have viewed Mrs. M's situation as a breach of the patient's self-
determination, but rather a result of a cultural tradition that both the patient and Mrs. M
had lived with throughout their lives.

It is clear from this discussion of the situations outlined at the beginning of this thesis
that an approach to healthcare decisionmaking and informed consent different from the
autonomy model currently practiced is needed. An open account of autonomy that allows
for individual management styles in decisionmaking, an understanding of individuals as essentially in relations with others both intimately and distantly, and a view of individualism as one of many ways of living one's life all contribute to a re-informed notion of healthcare decisionmaking and informed consent. It is a means of returning to the simple goals of informed consent as identified by the President's Commission. It is also a means of returning some of the art of healing in the roles of professionals in their interactions with patients, families and significant others within the context of healthcare.

Making it Work

In order for the kinds of fundamental shifts in thinking and behaviors to occur in healthcare as discussed in this chapter, there is at least one consideration that must be undertaken in bringing them about. There must be an essential effort in the education of professionals and the public for the shift to occur. The modes of thinking deeply embedded in the current education of professionals stem from the indoctrination of the professions with the individualistic model predominant in bioethics theory. Although it is true that not all of the healthcare professions embrace that model with the same degree of acceptance, nonetheless it is the model that predominates. The public has likewise accepted the individualistic model at least superficially, although much of the dissatisfaction with its limited views has originated from within their ranks. Contemporary bioethical theory arose from concerns about the misuse of medicine, research and medical technology, but in an effort to offer guidance it has espoused a particular view to the virtual exclusion of others. These three areas, education of the
public, redirection of the thinking of healthcare professionals, and reworking bioethical theory, need to be considered in terms of how to effect the changes needed in order to reframe healthcare decisionmaking.

The nature of the healthcare encounter, especially in institutions, is predominantly one in which the patient is ill or injured. Even in the clinic setting many patients enter the system seeking relief from a particular physical ailment. Daniel Callahan, widely known and respected as the founder of the Hastings Center and a bioethics theorist, has suggested that the experience of being sick or injured is an experience of being vulnerable, and when we are feeling vulnerable enough, we seek the help of others. That vulnerability creates a particular response in others. According to Callahan,

There is almost a universal sentiment...that there is some kind of mutual obligation to provide care. What is its basis? It is undoubtedly our shared sense that we cannot, alone or on our own, cope with the ravages of illness and death, even though they are our most private of experiences....It is the vulnerability that illness creates that most requires the response of others. I call that response one of caring....Caring should always take priority over curing for the most obvious of reasons: There is never any certainty that our illnesses can be cured and our death averted. Eventually they will, and must, triumph. Our victories over sickness and death are always temporary, but our need for support, for caring, in the face of them is always permanent.\(^19\)

From this view, the role of healthcare professionals is clearly one of attention to the needs of the patient. That attention should include the particularity of the person and
their relationships in an illness experience. The understanding that caring for patients as whole persons means including the patients' significant others, their ways of managing value decisions, traditions and beliefs that inform their identity, and their own definition of well-being even as they face the illness experience must become part of how professionals approach patients. Healthcare professionals must be educated in this way of thinking so that such considerations are not secondary but rather primary because these elements affect the meanings of health, illness and medicine for the patient. If the goal of benefitting the patient is to succeed, it must be in the terms of what benefits the patient seeks as meaningful to him or her.

The programs for healthcare education must be refocused to incorporate these changes throughout the students' experiences. An ideal program would include not only the science of medicine and medical treatments, but what it means to be a professional. A program such as that conceived by the Pew-Fetzer Task Force would be an excellent starting point. According to the Task Force, education of healthcare professionals must include the understanding and experiences of professionals as part of a community in which they provide a vital human service, even if they do not live in the immediate community in which they practice. Their skills must include not only technical expertise but the humanistic skills of communication, empathy and involvement. Understanding what it means to be a healthcare professional entails understanding what it means to be ill from many different perspectives as well as the moral nature of professionalism. These kinds of skills cannot be taught effectively by healthcare professions educators alone. They point to the need for interdisciplinary programs that value both science and the
humanities. Likewise it points to the need for education that takes place not only within the healthcare institution but out in the community as well.

The role of the public in the creation of the current system and model should not be underestimated. The appeal of a rights and liberties perspective concerning medical treatment as a backlash against medical paternalism is understandable. Although widely embraced by the public twenty years ago on the heels of the civil rights movement, the rights perspective over the ensuing years has not yielded the expected satisfaction with the current model. This is likely due in part to the feelings of isolation and depersonalization resulting from the role of professionals as dispensers of information and rights advocates without the trust and understanding of a healing relationship. If the role of professionals begins to change, expectations regarding that role on the part of the public will also change. If professionals are seen as participants in their care and the guard can be let down, it is likely that trust will reappear and genuine communication and exchange of knowledge will occur. Without the element of trust in the person as professional committed to the patient's benefit rather than other interests, the movement of the public away from litigious attitudes that fueled professional and institutional legal paranoia will not occur.

The standard approach in contemporary U. S. bioethics theory has been one in which principlism is espoused as the accepted method of moral reasoning and judgment. Most of the texts used today in medical ethics education hold this tradition paramount in the development of moral reasoning among students in medical ethics and healthcare students to a more limited extent. In fact, principlism has been called, "...the most
popular and influential product in the current bioethical marketplace.¹ The principle-based approach has become the standard for moral judgment in cases of medical ethical dilemmas. Understanding of these principles and particularly that of autonomy is considered essential. However, application of principles even with considerable understanding has at times served only to further detach professionals and patients from each other and the very personal, emotional and often heart-wrenching reality of the situation.

Changes in bioethical theory and practice must spearhead any efforts at changing the conceptions of professionals and the public concerning healthcare decisionmaking and informed consent. The multifaceted nature of considerations for a new paradigm in bioethics points to the need for a truly multidisciplinary approach to the "demi-discipline" of bioethics. There are certain basics which should be considered a core of any curriculum in the field. For example, the history of medical ethics and bioethics would give a background necessary for understanding the development of the practices of various healthcare professions, their codes of ethics, and the treatment of various issues within the respective professions. Theoretical foundations and methods of analysis in moral arguments give an appreciation and understanding of the nuances of different approaches in various theories. Familiarity with comparative analyses assists in distinguishing and relating the perspectives provided by law, public policy and religion on a particular issue. Knowledge of moral issues of professionalism provides a basis for understanding conflicts concerning professional responsibilities arising within the context of current healthcare policies. Cultural influences on approaches to bioethical issues for
individuals require understanding of these aspects of dilemmas and skills of mediating concerns of those involved. Finally, the areas of sociology, anthropology, literature and other non-traditional resources for medical ethics provide a rich source of information on various aspects relevant to bioethical theory. These interrelated multidisciplinary areas should be considered essential for the study and practice of bioethics.

Through such an integration of sources of study, bioethics theory and practice can pull away from its stuck position in individualism to embrace the expanded notions of autonomy, self, others and personal management decisionmaking styles to reshape informed consent. The lead of bioethical theory and practice will help the professions and the public move in this direction as it did following World War II. Toward that end, substantial support for innovative and integrated programs in contemporary bioethics should be essential in any considerations of how to implement the reconstruction of autonomy, decisionmaking and informed consent in order to support the diversity of our country and the basic values we share in healthcare.

Conclusions

This thesis has argued that there is a need to consider a shift in focus of healthcare professionals from rights and duties of independent individuals to attitudes and responsive relationships of healthcare professionals that support the diversity of individual patients encountered in the healthcare systems. The relationship between the professional and the patient is the center of all healthcare and it is a conduit for all kinds of information relevant to the success or failure of a therapeutic intervention. As such, it
functions as a factor in the psychological perception of satisfaction or lack of satisfaction in both patient and professional. Potentially it can likewise function as a conduit for the benefits of the art of healing missing in healthcare relationships that are trapped in the limitations of current definitions of self, others and appropriate professional interactions.

Relationships with others are equally important. Patients do not usually arrive on the doorsteps of the healthcare systems without current or prior relationships with others and within the community and society in which they live. Similarly, healthcare professionals usually do not function alone as solitary, isolated practitioners but in some manner of connection with other professionals in their own field or in other fields of practice. In addition, healthcare professionals usually describe themselves as serving a particular community within which they practice. It is therefore consistent to include effective relationships with and within the community and among all practitioners as essential in considering an appropriate model for the role of healthcare professionals in relations with patients.

This thesis has sought to answer the question, Has autonomy misinformed informed consent? More specifically the question can be understood as, Has an autonomy model for healthcare in general and particularly decisionmaking, functioning as a paradigm for expectations and relationships between healthcare professionals and patients, misinformed the process and thus the intent of self-determination through informed consent? This question has come to the fore due to emerging data on cross-cultural issues in informed consent and the growing experiential knowledge of bioethicists in the trenches. Such situations as described in Chapter 1 point to issues of culture, spiritual
beliefs, and other non-physiological factors which should be considered in healthcare interactions and decisions. It also recognizes the devastation of relationships (e.g., surviving spouse and family, surviving spouse and healthcare professionals) that sometimes occurs under the current obsession with one way of viewing self, others and professional responsibilities.

If meaning and depth are to be given to the principle of respect for individual persons' values and perspectives, then a deeper understanding and appreciation of differing values and worldviews needs to be seriously undertaken by healthcare professions. This does not necessarily mean that there need be different sets of moral rules concerning informed consent for each ethnic group, nor that all members of a particular ethnicity will conform to the traditional values of that group. Rather, it suggests that healthcare professionals pay due attention to and value individual patients as whole persons with knowledge, values, experience and relationships shaped in part by a view of self and others derived from the context of their lives. To attempt to accomplish this within a rights based framework and scientific paradigm of twentieth century healthcare professional traditions would be virtually impossible. An alternative framework that supports values common to humanity rather than a privileged view could serve as a catalyst for movement of the entire healthcare system paradigm in a direction that serves the needs of communities, individual members of society and professionals alike. Although aimed at the healthcare professions and medical culture, its force and broad application could manifest in a similar reconstruction of many other areas of society, and result in a truly integrated, humanity-centered nation that values its diversity as necessary for its survival.
NOTES


6. For a more comprehensive discussion of these kinds of issues and how they can be accounted for in an open definition of autonomy, see Double's article which more fully develops this account, esp. 72-79.


10. Emanuel and Emanuel, 2222.

11. President's Commission, (1982), 2


14. Id.

15. Ibid., 35.

16. Id.


18. In most states including Nevada, state laws allow for such standards of treatment as CPR for patients in end-stage disease especially if they are already in institutional settings. This is due to an acknowledgement of the desirability of maintaining the integrity of the profession of medicine for the benefit of society. When a treatment holds no value in furthering the goals of medicine in benefiting the patient beyond merely sustaining biological life, it is usually deemed inappropriate treatment for that situation. However, the state of New Jersey allows for such treatment in cases where the religious beliefs of the patient would preclude the limitation of life-sustaining treatments.


20. The Pew-Fetzer Task Force was a collaboration between the Fetzer Institute, a non-profit educational organization promoting research into healthcare methods that utilize the principles of mind-body phenomena, and the Pew Health Professions Commission, a program of the Pew Charitable Trusts. The partnership began in 1992 with its aim being to examine ways to develop health professions curricula in various programs that promote an integrated approach to healthcare and that affirm the interaction of biomedical and psychosocial factors in health. For greater details of its purpose and activities, see C.P. Tresolini and the Pew-Fetzer Task Force, Report of the Pew-Fetzer Task Force, (San Francisco, CA: Pew Health Professions Commission, 1994); and Pew Health Professions Commission, Health Professions Education and Relationship-Centered Care: Conference Proceedings, (San Francisco, CA: UCSF Center for the Health Professions, 1994).


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