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Value Conflicts in Cross-Cultural Medicine: The Role of the Family in Medical Decisions -- Chinese Patients and Western Practitioners

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by

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to Mom, Dad, Bec, and Heather for showing me, through their love,
the meaning of connection

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Introduction

The development of the discipline of bioethics in the United States over the last twenty years produced major changes in both the practice of Western medicine and in how medical decisions are made. As technology gave medicine the ability to expand the bounds of life and death, the need to discuss and resolve the consequent ethical dilemmas gave rise to the development of bioethics.

Bioethics reflects the attitudes and orientations of Western medicine. Anthropologist Patricia Marshall defines bioethics as "inquiry into moral dilemmas created by the theoretical and practical application of technological developments associated with the Western biomedical sciences."[1] Bioethics seems to enter into the daily existence of most people, from those waiting twelve hours in emergency rooms, to those determining policy on abortion, to those reading newspaper articles on physician-assisted suicide. As such, bioethics has become an inextricable part of U.S. society. This is in contrast to "medical ethics," a term which encompasses medical professional relations between practitioners and patients, between different practitioners, and between practitioners and society. Medical ethics can refer to any culture, regardless of its level of technological advancement.

With Western medicine's emphasis on diagnostic techniques and defined disease entities, the development of bioethics reflected two needs: one, the need for a framework to discuss the new moral dilemmas; two, the need for a logical process to resolve them. "Ethics consultations" were developed to meet these needs; a physician facing an ethical difficulty calls the institutional ethicist or consultation committee to help him or her resolve the situation. This procedure mimics the way a medical specialist is consulted for a particular organ system problem. Self-defined, bioethicists hail from various disciplines including medicine, philosophy, theology, law, anthropology, and public health.

Most bioethics discussions involve a "principlist" approach developed by Beauchamp and Childress.[2] It appeals to four guiding principles -- autonomy, beneficence, non-maleficence, and distributive justice -- which, when applied to an ethical situation, often produce an unambiguous course of action. This formulaic method resembled the way in which medical decisions were often made, and thus increased the acceptability of bioethics consultations.

I suggest, however, that such an approach runs the danger of reducing ethical debate to a rigid procedural exercise of listing principles and weighing theoretical results. Because of its narrow focus, some anthropologists and philosophers have criticized this procedural structure of bioethics discussions. In recent years, a few have proposed new theories which approach bioethical scenarios from other directions. Contextualist theories from Hoffmaster[3] and Thomasma,[4] casuist theory from Jonsen,[5] caring ethics from Gilligan,[6] and virtue ethics[7] have all been proposed as alternative theories to the principlism of Western bioethics. However, principlism still holds the dominant position in Western bioethics, and the principles frame most discussions of bioethical problems.

One difficulty inadequately resolved by principlism concerns cultural differences. While there have been attempts (notably from medical anthropology) to address cultural differences in medicine and health care, few have attempted to discuss the problems of conflicting cultural differences within a *single* medical system.[8] Since American bioethics bases its discourse on the Western philosophical approach, the principles, values, and guidelines which emanate from the bioethics literature[9] tend to reflect this

Western orientation. However, other cultures which do not share this philosophical orientation will undoubtedly question the American approach to both bioethics and clinical practices influenced by bioethics theories.

The problem arises, then, when individuals from other cultures interact with the Western bioethics model. Since cultural conceptions of health and medicine frame a patient's understanding of a medical problem, an "ethics consult" based on the Western model of bioethics risks approaching the problem from a point of view the patient would neither understand nor relate to. An illustrative example is that of the principle of informed consent. Informed consent to treat requires a thorough understanding of the purpose of the procedure and the risks involved. Some cultures view telling a patient all the information about a medical procedure as a violation of the trusting bond between the physician, the patient, and the family. Providing informed consent could foster a sense of mistrust and would not likely engender future cooperation between the patient, the patient's family, and the health care team.[10]

When the patient's (and family's) values are not reflected by the Western model of bioethics on which the system frames its moral imperatives and duties, patients and their families may not understand the procedural approach (e.g. obtaining informed consent) or the established principles of the Western bioethical system. There is no facile solution. If the bioethicist required conformity to the Western principles, would she cause harm to the patient/practitioner relationship by fostering a sense of distrust of the physician? On the other hand, if the bioethicist acquiesced and acted according to the patient's cultural values, would she be opening a Pandora's box of culturally appropriate but, to our moral system, ethically questionable actions, e.g. female circumcision, infanticide, etc.? To suggest, as a policy matter, either extreme seems both overly simplistic and naive.

One possible course of action when confronted with cross-cultural ethical conflict is to assess the the philosophical and practical advantages and disadvantages in each approach. Exploring a telling example of such conflict will prove helpful in understanding the complexities of these situations. One such cross-cultural conflict centers on the appropriate role of the family in medical decision-making in Western vs. Chinese medical systems.

The Family and Decision-Making

The family in medical decision-making structures is currently undervalued by Western medicine. When patients and their families from Chinese cultures encounter this Western model, they often find that their own cultural values do not coincide with certain Western notions of autonomy, specifically the values of truth-telling and informed consent.

The conflict arises as follows: If traditional Chinese values hold that the family should make all the decisions for an ill patient, and the values of Western medicine hold that the principle of individual autonomy requires the patient to make all the decisions, which should prevail? I believe a solution lies in a compromise position which allows an increased role of the family in Chinese medicine but which guards against abuse or neglect of patients. By examining each cultural approach and applying it to a test case, a position emerges which retains some of the advantages of each system.

This project addresses this particular cultural conflict by first considering the history of the development of medical ethics in both Western and Chinese systems. The first three chapters discuss notions of health care and bioethics, focusing on the roles and responsibilities of the patient, family, and physicians.

Chapter 4 discusses the conceptions of the self, person, and community in order to understand the interplay of individual values and cultural systems.

Chapter 5 discusses conflicts between cultures, the historical development of cognitive and moral relativism, and the need to respect the values of other cultures.

Chapter 6 discusses the application of each medical and ethical system to the test case and outlines the advantages and disadvantages inherent in each system, considering differing conceptions of personhood and cultural relativism.

Finally, in chapters 7, 8, and 9, I propose various approaches to the test case and critique each one.

Chapter 10 offers policy recommendations on various levels to help clarify the nature and resolution of cross-cultural differences based on the advantages and disadvantages of each previously discussed approach.

While it is important to consider this as a discussion of two cultural systems, three points must be remembered throughout the paper. First, when the term "Chinese" is used, it only refers to a generalization of Chinese culture based on readings, references, etc. The degree to which any given Chinese patient and/or family reflects these categorizations depends on many factors, including social status, religious affiliation, place of origin, and degree of acculturation. Therefore, it is important to understand the intent of this work within its limited context: to discuss *potential* cultural conflicts and their resolution in the setting of medical decision-making. Second, "Western" medicine refers to the allopathic tradition derived from predominantly European medical systems and practiced in the United States. References to "Western" doctrine or legal theory refer, again, to the American orientation. Third, while this is a study of particularly Chinese systems and values, the concepts apply to the larger issue of ethnic variation within societies,[11] cultural pluralism, and the intersection of differing value systems in a diverse and changing world.

In addition, there are dangers in misapplying or misconstruing this type of cross-cultural study and the production of any set of guidelines or model for interaction between patients and physicians. The worst possible result of these types of discussions about cultural bias and sensitivity would be the recommendation of a reductionistic approach to decision-making. Concepts of culture would be reduced to a checklist of prominent characteristics: Chinese people do A, Swedes require B considerations, Latinos discuss C with the family, etc. This sort of approach runs a risk equal to applying Western standards uniformly to all people. Patients would be judged and would receive care based on perhaps incorrect assumptions. Much like informed consent and DNR policies, physicians could become slaves to filling out forms rather than encouraging open and unambiguous discussion with patients and their families.[12]

This project attempts to outline the potential value conflicts and solutions of Chinese patients in the Western medical system. It is intended to explore differences in the expectations of Chinese patients and families, based on traditional Chinese health care and their conception of the "person." This project also attempts to provide compromises between Chinese and Western values by examining three models of health care decision-making which involve the family more. These models can be applied to any provider-patient interaction -- not just those involving Chinese patients.

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[1] Marshall, Patricia, "Anthropology and Bioethics," Medical Anthropology Quarterly, 6 (1), p. 52.

[2] Beauchamp and Childress, Principles of Biomedical Ethics. 3rd ed., (New York: Oxford University Press, 1989).

[3] Hoffmaster, Barry, "Morality and the Social Sciences," Social Science Perspectives on Medical

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Ethics, ed. George Weisz, (Philadelphia: University of Pennsylvania Press, 1990), pp. 241-260.

[4] Thomasma, David C. The Context as Moral Rule in Bioethics, Journal of Bioethics 5: 63-79.

[5] Jonsen, Albert, Casuistry in Clinical Ethics, Theoretical Medicine 7 (1): 65-74. See also Jonsen, Albert and Toulmin, S., The Abuse of Casuistry: A History of Moral Reasoning, (Berkeley: University of California Press, 1988).

[6] Gilligan, Carol, In a Different Voice: Psychological Theory and Women's Development, (Cambridge, MA: Harvard University Press, 1982) also see Holmes and Purdy, eds., Feminist Perspectives in Medical Ethics, (Bloomington: Indiana University Press, 1992).

[7] Pellegrino, Edmund, "Character, Virtue, and Self Interest in the Ethics of the Professions," Journal of Contemporary Health Law and Policy 5 (1989): 53-73.

[8] A notable exception to this is the Western Journal of Medicine that has devoted two issues entirely to cross-cultural medicine. Cross-Cultural Medicine, Western Journal of Medicine 139 (Dec 1983). Cross-Cultural Medicine a Decade Later, Western Journal of Medicine 157 (Sep. 1992). See also Meleis and Jonsen "Ethical Crises and Cultural Differences" Western Journal of Medicine 138 (June 1983): 889-893.

[9] Beauchamp and Childress, Principles , Englehardt, H. Tristam, Jr. The Foundations of Bioethics, (New York: Oxford University Press, 1986).

[10] Meleis and Jonsen "Ethical Crises and Cultural Differences" Western Journal of Medicine 138 (June 1983): 889-893.

[11] Leiban, Richard, "Medical Anthropology and the Comparative Study of Medical Ethics," Social Science Perspectives on Medical Ethics, ed. George Weisz, , (Philadelphia: University of Pennsylvania Press, 1990), pp. 230-231.

[12] Ventres, William, et al., "Limitation of Medical Care: An Ethnographic Analysis," Journal of Clinical Ethics 4 (2) (Summer 1993): 140-141.

CHAPTER 1: Medical Ethics -- A Field of Study

Medical systems, or the "spectrum of resources that meet the demand for health services"[13] in different cultures, have long been a topic of study for anthropologists. Medical systems can only be understood within historical, political, and economic contexts. Within these systems, concepts of health and disease vary. These variations include the objects of concern (illness, disease), the conceptualizations about the objects of concern (theories of causation, explanatory models), symbolic meanings, healers who treat the illnesses, and the social practices and institutions that encompass these.[14]

Medical ethics adds another category to the field of medical anthropology. Fabrega, one of the few to approach medical ethics as a separate field of cross-cultural research, defines medical ethics as "the precepts and standards of how practitioners should conduct their work given their status in the society."[15] In each system, relations are established between providers, patients, and others involved in medical interactions. Cultural and social factors within each system affect these relations as "practitioners and their clients are bound to the social standards of behavior and morality of the group, and out of this morality is constituted the special morality of healing."[16] As each medical system functions according to certain accepted practices and relationships, each has its own system of medical ethics. As such, the comparison of different systems of medical ethics emerges as a separate area of inquiry within medical anthropology.

Little has been written in the past regarding medical ethics as a field of study for medical anthropologists.[17] Medical anthropologists may feel that as they study a culture and its approach to illness -- elucidating the process of description, causation, and healing -- they are already describing its "medical ethics." In doing so, some medical anthropologists may believe they obviate the need to discuss medical ethics as a separate category. It is only recently that the academic pursuit of medical ethics has become a global subject.[18]

At this stage, it is important to distinguish between the terms *bioethics* and *medical ethics*, as the two are often used interchangeably. While traditional medical ethics has been defined by the Encyclopedia of Bioethics as "an extensive range of admonitions varying with culture, time, and type of medicine, and dealing with demeanor... and other behavioral possibilities within medicine,"[19] bioethics is best considered a new category within medical ethics. The discipline of bioethics emerged as a response to recent Western biomedical advances and technologies. These technologies have brought increasing control over various illness processes and power over the very bases of life itself. "This capacity directly to manipulate biological systems has challenged traditional definitions of life, human identity, human integrity, and human terminality."[20] This new ability has brought to the fore questions about social policy regarding these technologies, the definition of personhood, and the manipulation of life itself. In this project, when discussing ethical systems of different societies, I refer to "medical ethics." When the discussion refers to the norms of Western (specifically American) society, I employ the term "bioethics."

The Practitioner-Patient Relationship

This project focuses on the imperatives of the practitioner-patient relationship and the conflicts that arise when a patient from another culture encounters the Western medical system. The therapeutic bond between patient and practitioner forms when the patient's illness cannot be helped by ordinary remedies or familial advice, and the patient seeks a person with special knowledge, training, and authority. It is this special knowledge that necessitates specific proscribed expectations within the physician-patient relationship; the two "form a relationship characterized by trust, obligation, compassion, and caring."[21]

The nature of the specialist, with specific knowledge and theories of disease causation, creates a psychological distance between the patient and the practitioner as the formalized interpretation of the disease differs from the personal and private views of the patient. As Fabrega states,

> The varying interpretations of illness create tensions between humanitarian/caring as versus technical/impersonal directives in medical practice and the latter in turn constitute conditions for a psychological distance between practitioners and patients in all of the Great Traditions of Medicine.[22]

Fabrega asserts that the development of a formalized "medical ethics" stems from the specialized professional role of the healer and the power differential it establishes between practitioner and patient.

The Problem of Cultural Conflicts: A Case

While it is possible to compare medical ethics of different societies by looking at the relations between practitioners and patients in those societies, complications arise when the practitioner and patient *within* a society come from different cultural, and therefore medical ethics, systems. If a patient holds certain values and beliefs about disease causation, presentation, and treatment and the practitioner holds differing beliefs, the two may have conflicting expectations regarding the ensuing encounter. This type of complication frequently occurs within hospitals in the U.S. which are caring for increasing numbers of immigrant patients.

The following case provides a telling example of the profound conflicts faced by the patient, the family, and the health care team when a patient's cultural system clashes with the established "standard of care" administered in the Western health care system:

Case 1: Mrs. Lee is brought to the hospital emergency room of the local county hospital for chest pain and shortness of breath. Diagnostic tests reveal that her chest pain is due to a pneumonia caused by an undiscovered breast cancer metastasizing to the lungs. The tests reveal she has widespread metastases and she does not have much longer to live. Mrs. Lee does not speak English and interpreters are scarce. Her husband and children translate for her. When they are told about the diagnosis in the hospital room, it is unclear exactly what gets translated to Mrs. Lee. Afterwards, the family meets with the doctors and nurses involved in her care and asks that all communication go through them. With further discussion, they reveal that they don't want her to know the real diagnosis. They say that it is not what should be done given her condition and the progression of her illness. They reason that if she knew the diagnosis, she would lose all hope and die. Furthermore, they ask that they be consulted about all future tests and/or proposed therapies.[23]

The two main issues presented by the case are as follows: one, the family intervenes between the physician and patient and asks that the patient not be told of her diagnosis; two, the family attempts to decide which medical therapies to pursue for the patient. How should the health care team react? What is their justification for treating or not treating, telling or not telling?

Bioethics norms hold that a patient has a right to full information about her diagnosis and any therapies, if desired. Assuming that the health care team follows the Western orientation, honoring the family's request would contradict all current approaches to medical decision-making based on the institutions of individual autonomy, informed consent, and truth-telling. Truth-telling holds that patients should be told the truth about their diagnoses so that they can make the most informed choices about their treatment options, including the choice to refuse further treatment. The notion of informed consent holds that patients can only consent to tests, procedures, or therapy when they have an adequate understanding of why the test is being done, the risks involved, and the proposed therapeutic benefits.

However, if the perspective of the family reflects the patient's cultural heritage, shouldn't the request be respected? The approaches of each culture -- Chinese and Western -- present different answers; a clear solution is not apparent because the approaches of each are diametrically opposed.

The resolution of the dilemma first requires an understanding of three relevant topics: differing systems of medical ethics, varying conceptions of selfhood, and the notion of relativism. First, a discourse on the medical ethics of Western and Chinese systems will frame the discussion in terms of the health care standards and expectations of each. Over the course of the next two chapters (Chapters 2 and 3), I will compare the two systems of medical ethics based on their historical development, the main principles embodied by each, and new developments in each system. I will conclude by addressing how each system of medical ethics shapes the expectations of the practitioner, the patient, and the family in the medical encounter. These last points provide a deeper look into the expectations of representatives from different cultures when they conflict.

Following the summary of different ethics systems, a brief discussion (Chapter 4) of the conception of self and personhood in Western and non-Western cultures explains how differing conceptions of personhood are central to understanding medical decision-making in different cultures. Finally, notions of relativism must frame the discussion of differing cultural values (Chapter 5). Should all cultural beliefs be respected regardless of the situation? Are there criteria for accepting or not accepting differing cultural beliefs?

Only after the elucidation of these topics in the following chapters can I address the problems presented by the test case, offer some approaches towards a resolution, and make policy recommendations regarding cultural conflicts about autonomy and informed consent.

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[13] Unschuld, Paul, Medical Ethics in Imperial China, (Berkeley: University of California Press, 1979), p. 4.

[14] Leiban, Richard, "Medical Anthropology," p. 221.

[15] Fabrega, Horacio, Jr., "An Ethnomedical Perspective of Medical Ethics," Journal of Medicine and Philosophy 15 (1990): 594.

[16] Fabrega, Horacio, Jr., "An Ethnomedical Perspective," p. 595.

[17] Leiban, Richard, "Medical Anthropology," p. 221.

[18] The first book on cross-cultural views of medical ethics was by Robert Veatch, entitled Cross Cultural Perspectives in Medical Ethics: Readings, (Boston: Jones and Bartlett, 1989). In addition, the International Bioethics Institute was just started a few years ago, specifically devoted to the study of international heath care ethics.

[19] Under the heading Bioethics in Encyclopedia of Bioethics, Warren T. Reich, ed., (New York: Free Press, 1978), p. 119.

[20] Fabrega, Horacio, Jr., "An Ethnomedical Perspective," p. 613.

[21] Fabrega, Horacio, Jr., "An Ethnomedical Perspective," p. 597.

[22] Fabrega, Horacio, Jr., "An Ethnomedical Perspective," p. 606-7.

[23] This case is loosely based on a case presented in the Western Journal of Medicine. It has been slightly modified for my own purposes, but retains many similar characteristics. Muller, Jessica H. and Desmond, Brian, "Ethical Dilemmas in a Cross-Cultural Context: a Chinese Example," Western Journal of Medicine 157 (Sept. 1992): 323.

CHAPTER 2: Western Medical Ethics

Medical ethics in the world of the American biomedical tradition has drastically changed in the last few years. Medical ethics has broadened its focus to include not only proscriptions of conduct for health professionals, but also discussions of the rights of patients, and legal constraints on medical decisions. After delineating the development of bioethics from medical ethics, I will consider one of the main principles of bioethics, autonomy, and its impact on the roles of the patient and family.

Though medicine itself has been called the "youngest science" because of its relatively recent advancement into the realm of curing over caring, bioethics could be called an even younger discipline because of its creation in the past 30 years. Edmund Pellegrino, whom some regard as one of the most influential thinkers of the bioethics movement, has characterized three periods in the history of medical ethics: a quiescent period, a period of principlism, and a period of antiprinciplism.[24] These periods overlap somewhat and I suggest the only true distinction contrasts the early years of medical ethics and the last thirty years.

In the years prior to the 1960's, medical ethics changed little from the early days of medicine and the Hippocratic oath. The 2500 year old oath and the books of the Hippocratic corpus contain ethical precepts such as beneficence, non-maleficence, and confidentiality. In addition, the ancient physicians expounded on the evils of surgery, abortion, sexual relations with patients, etc. The texts also tended to emphasize habits of dress, etiquette, gossip, and consultations with other physicians.[25]

However, rules or principles as measurements of moral choice were given little emphasis, as was the physician-patient relationship.[26] Philosophers wrote on topics such as suicide, abortion, and euthanasia, but rarely on what Pellegrino calls the "fulcrum" of medical decisions and patient well-being -- the therapeutic relationship between physician and patient. Instead of discussing duties specific to medicine, these precepts described the ideal comportment of physicians. "The virtuous physician was one habitually disposed to act in conformity with the virtues of courage, temperance and justice and in accord with the moral precepts of the oath."[27] Medical ethics was defined solely by the profession.[28]

The Rise of Bioethics

The 1960's and early 1970's provided a colorful backdrop for the abandonment of this profession-centered ethic. Social and technological events of these times were pivotal in creating modern-day bioethics.

The social backdrop of the 1960's provided one impetus. Pellegrino attributes part of the development of modern-day bioethics to the general upheaval of moral values during the 1960's. The spread of participatory democracy through the civil rights and women's movements, consumer activism, a better educated public, an increased sense of ethnic identity, and a growing distrust of authority and institutions produced profound changes in American society. These factors led many to question "the moral grounding of society in general and of medicine in particular"[29] and led to inquiry into medical ethics.

In addition, the exponentially increased fund of medical knowledge and the development of new technology that would extend life, redefine death, and attempt to control the human condition caused many to question the direction medicine had begun to take.[30] One of the first bioethical issues to arise, the rationing of limited medical technology, was discussed by a committee formed to evaluate prospective applicants for renal dialysis at a Seattle hospital in 1962. Faced with too many renal failure patients and too few dialysis machines, the committee confronted a difficult question: Should dialysis be provided to patients on a first-come, first-serve basis, or be prioritized through a ranking system? This was the first time such dilemmas were openly acknowledged. In response to these new dilemmas, the first of many bioethics research institutes were founded during this time. The Hastings Center was founded in 1969, followed by the Joseph and Rose Kennedy Institute of Ethics at Georgetown University in 1970.

In addition to new technology, revelations of ethically questionable research prompted bioethicists to focus not only on medical practice, but on problems and ethics in medical research as well. These ethically dubious projects included the Willowbrook experiments in 1972, and public revelation of the Tuskeegee study in 1972.[31] In response to increasing numbers of questions about research ethics, the National Heart and Lung Institute formed a panel in 1972 to assess the "ethical and moral implications of the totally implantable artificial heart."[32] Later, the federal government established the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research whose purpose was to study the "principles governing biomedical research."[33] The product of this national commission was the Belmont report, which produced two significant results: first, it applied the principles of beneficence, the respect for autonomy, and the respect for justice to research; second, it suggested the creation of Institutional Review Boards at each research institution to address these ethical concerns at the local level. [34]

Society's concerns about ethically questionable research and the potential applications of new technology caused many in medicine and in government to worry about the future and ethics of medicine. Albert Jonsen, in his discussion of the rise of American bioethics, suggests that since

American moralism tended to favor absolute opinions about what is morally acceptable, bioethics emerged as a way to bring some sense of order back into the chaotic world of scientific discovery.[35] This, he posits, explains why principles of biomedical ethics have become so popular and dominating in medical ethics. The Belmont report and the principles applied to research were merely "a product of American moralism, prompted by the desire of congressmen and of the public to see the chaotic world of biomedical research reduced to order by clear and unambiguous principles."[36]

Prima Facie Principles and the Big Four

The theory of prima facie principles proposed by Ross[37] and advocated by Beauchamp and Childress gained acceptance and application in the new bioethics. Ross' theory states that principles exist which should be followed unless there is some counterbalancing duty or pressure to overrule them. If such a duty exists, then it is ethically justifiable to overrule the first principle. The actual course of action of a moral agent is determined by weighing all prima facie principles. As Beauchamp and Childress state, prima facie principles "constitute strong moral reasons for performing the acts in question, though they may not always prevail over other prima facie duties."[38]

The principles that Beauchamp and Childress consider essential to medical ethics are beneficence, non-maleficence, respect for autonomy, and justice. (These have been affectionately called the "big four" by proponents and less affectionately called the "Georgetown Mantra" by critics -- implying that they are often blindly and automatically followed.)

Some have argued that the advantage of such a set of principles is that they often produce similar recommendations in a given case, regardless of the orientation of the ethicist. The principlist approach provides a set of guidelines by which both utilitarians and deontologists can agree on certain outcomes of a given case,[39] thereby lessening the amount of debate over determination of the good. Similar courses of action are suggested, whether they are justified on the basis of their increasing overall utility or by their adherence to certain universally acceptable rules or duties.

The principle-based method had two other advantages. First, the fact that the principles do not *directly* threaten other aspects of medicine, such as abortion or euthanasia, made their acceptance palatable. Second, the formula of applying each principle to a given case provided a compelling model of ethical consultation for clinicians because it mimicked the decision tree used for medical problems.

A weakness inherent in the system concerned the possibility of principles themselves leading to different recommendations. Since Beauchamp and Childress did not order their principles in a hierarchical way, conflicts between principles could arise. Realizing this problem, Beauchamp and Childress provided a system for resolving conflicts between competing principles. They provided four requirements for "justified infringements" of a prima facie principle: first, the moral objective must be achievable; second, no morally preferable alternative is available; third, the smallest infringement possible must be sought; fourth, the agent must act to minimize the effects of the infringement.[40] Physicians found this stepwise approach to be in accord with the way they learned how to practice medicine. This made ethics consultations much like asking for a neurology or other specialty consultation; the "workup" was methodical and defined.[41]

The wide acceptance of this approach indicates the attractiveness of such a system in the clinical setting. Hundreds of students of bioethics have learned this "method" through intensive bioethics courses taught at The

Kennedy Institute for the past 18 years. Upon completion, these graduates go on to teach their own courses and direct academic bioethics centers in other parts of the country. Literally thousands of clinicians, medical students, public health professionals, and others have learned this system of medical ethics analysis.

Despite the wide acceptance of this system, many individuals hesitate to accept formulaic application of the four principles so readily. While the first two of these principles correspond to the Hippocratic principles, the other two -- respect for autonomy and justice -- are relative newcomers. The principle of autonomy seems particularly difficult to reconcile with Hippocratic tradition.

The Emergence of Autonomy

The historical tradition of physician paternalism left little room for autonomy of the individual (i.e. the patient) in the physician-patient relationship. This paternalistic stance included instances of physicians concealing a difficult or terminal diagnosis from the patient; indeed, revealing a terminal diagnosis was thought to eradicate hope and worsen the patient's condition. The justification for such concealment of information derived from thousands of years of medical tradition. Decorum XVI of the Hippocratic corpus stated that it would be best to conceal difficult information from patients because upon receipt of such information, "many patients... [had] taken a turn for the worse."[42] In a study of oncologists published in 1961, this was still the dominant opinion.[43] To reveal a terminal diagnosis and to have an open window in the room was considered a prescription for suicide.

Over the past twenty years, though, through a variety of social and legal pressures, the physician-patient relationship has been transformed into one which respects autonomy much more than before.[44] Both the rise of legal guidelines for informed consent and the durable power of attorney for health care, as well as patients' rights movements in birthing and hospice, exemplify this rise of patient autonomy. In addition, autonomy is viewed as more "consistent with the individualistic temper of American life, which emphasizes privacy and self-determination."[45] This accordance with the "temper" of American life results in autonomy often taking precedence over other principles when there is a conflict between principles. While this "temper" existed before the 1960s, the legal constraints and patients' rights movements have only recently reversed the dominant paternalistic stance of the medical community.

Current Legal Requirements and Professional Opinions

The first mention of informed consent dates back to 1956 in the context of informing patients about risks associated with particular procedures. The phrase "informed consent" was first mentioned in a *amicus curiae* brief filed by the American College of Surgeons to the California Court of Appeals on behalf of a physician being sued for malpractice. Justice Bray, in his opinion regarding *Salgo v. Leland Stanford Jr. University Board of Trustees* (1957), adopted the phrase verbatim from the brief and acknowledged the duty of a physician to provide any facts necessary to form an intelligent and informed consent for a treatment.[46] While Bray immediately proceeded to dilute the opinion by tempering the physicians' duty to disclose all information with allowance for physician "discretion," the issue of informed consent was raised.

In 1972, the Supreme Court of California ruled that physicians have a duty to disclose information regarding a patient's illness since the patient depends on the physician for information during the decision process.[47] In

1980, the Supreme Court of California ruled that the duty to inform applies not only to information regarding risks of a particular procedure, but extends to other types of information which would be important to know. In 1993, the court ruled that physicians should provide

> all material information -- information that [the] physician knows or should know would be regarded as significant by [a] reasonable person in the patient's position when deciding to accept or reject [a] recommended medical procedure.[48]

While it upheld its 1980 opinion in favor of informed consent, the court ruled in favor of the defendant, an oncologist who declined to give a cancer patient specific mortality rates for his disease even though the patient had indicated in a questionnaire that he wanted to be told the "truth" regardless of the severity of his condition. This suggests that the California Supreme Court in principle believes that patients have rights to any information which may be helpful to them, but still allows physicians much discretion in determining which information is relevant. Apparently the court does not consider mortality rates to be information that a "reasonable person" would find helpful in decision-making.

While the paternalistic stance is questioned in the courts, the provisions for withholding information for the patient's good are still reflected in many professional medical codes. The Council on Ethical and Judicial Affairs of the American Medical Association publishes the official opinions of the AMA. The 1989 Current Opinions publication states that a patient's "right to self-decision can be effectively exercised only if the patient possesses enough information to make an intelligent choice." The statement, however, outlines two possible exceptions to this policy: one, when the patient is incompetent and cannot make these decisions; two, "when risk-disclosure presents such a serious psychological threat of detriment to the patient as to be medically contraindicated."[49]

A similar position is held by the American College of Physicians. Their 1993 Ethics Manual includes guidelines for using disclosure as a general policy.

> Disclosure to patients is a fundamental ethical requirement. However, society recognizes the "therapeutic privilege," which is an exemption from detailed disclosure when such disclosure has a high likelihood of causing serious and irreversible harm to the patient.[50]

The statement goes on to warn physicians to not invoke this privilege too broadly, though, as it could "undermine the entire concept of informed consent."

Foundations of Autonomy

The philosophical foundations of autonomy provide a framework for understanding the limits of autonomy itself. After presenting the major historical formulations of autonomy in Western thought, I will analyze the current concept of autonomy and the recent debates and conflicts about its appropriateness in some situations.

Autonomy allows individual choice. This value derives from hundreds of years of Western philosophical thought, starting with the Greeks and Romans and culminating in the works of Immanuel Kant and John Stuart Mill. Kant's justification for autonomy comes from his insistence on the rational power of individuals to act independently. His formulation of the categorical imperative is that one must "Act in such a way that you always treat humanity... never simply as a means, but always at the same time as an end."[51] It is imperative to recognize the capacity of free and rational beings to choose for themselves. It is only when we respect others' ability to choose for themselves that we respect their autonomy as rational agents.

Mill offers a somewhat more developed discussion of autonomy in his essay entitled On Liberty (1859). In it, Mill ponders the power of society to impose its views on individuals. His formulation discusses liberty as a supreme value. "The only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not sufficient warrant."[52] He bases his argument on the belief that the ability to frame one's life plan or goals is necessary for the development of individuality, which he believes holds the foundation for human well-being.[53]

These arguments for autonomy represent strong arguments against paternalism and in favor of informed consent in health care. The historical role of paternalism has traditionally been justified on Utilitarian grounds with the argument that the negative effects of losing one's option to choose will be counterbalanced by a physician's determining the "best" treatment. However, the arguments for individual autonomy would suggest that even a net balance of positive over negative results still could not justify the infringement upon a person's right to choose.

Arguments Against Autonomy

Some have argued recently that autonomy has held too high a place in medical ethics discussions. Medical ethicists[54] are now suggesting that autonomy can overly control the discussion and that other equally important principles were neglected during the formative years of bioethics. Jonsen suggests that during bioethics courses, autonomy as a principle readily takes hold among students because it is easy to apply to challenging cases and arrive at an answer. As bioethics students gain experience and mature intellectually, they become more comfortable with the conflicts in principles that make moral philosophy interesting.[55]

Pellegrino has discussed the deficiencies of autonomy and the effect it has on the physician-patient relationship. First, he states that autonomy adds a strongly legalistic quality because it often is used in reference to invasion of privacy, tort law and leads to a "moral minimalism" or "a fulfillment of only what is specifically proscribed."[56] Pellegrino also suggests that the strong emphasis on self-determination minimizes the physician's obligation of beneficence. Perhaps more importantly, there is a prevailing attitude that the emphasis on autonomy has generated a "cult of moral privatism, atomism, and individualism that is insensitive to the fact that humans are members of a moral community;" this leads to conflicts between the rights of individuals and the rights of larger bodies such as families, clans, and societies.[57]

Even Childress, one of autonomy's strongest proponents, states that when autonomy has too much weight in the discussion, other values such as beneficence and care can be minimized or forgotten. In other words, when conflicts between principles arise, autonomy often carries too much weight. The resolution which safeguards autonomy can neglect the other principles. Childress states that sometimes "other principles outweigh or override the principle of respect for personal autonomy."[58] He affirms, however, that autonomy must remain as a guardian against the enforcement of "the good" of others. Without autonomy, individuals lose moral agency; their decisions are not important.

Implications for the Patient

In current medical practice, references to the "institution of autonomy" often dominate the discussions surrounding a patient's care. This primary role of autonomy is reflected in and reinforced by the liability a physician faces if she fails to obtain informed consent. A number of publications regarding the practice of informed consent and its necessity have appeared because of this new concern of autonomy. These articles discuss autonomy not from the viewpoint of legal necessity, but from a moral imperative.[59]

The importance attributed to autonomy is further shown in the attempt to preserve an individual's autonomy in the future, even when she is no longer competent. The growth of living wills and the Durable Power of Attorney for Health Care are examples. On these written documents, an individual can express her wishes about what type and how much health care she wants to receive if she is incompetent and unable to make those decisions independently. In fact, using the DPAHC, a person can *legally* assign a surrogate decision-maker to act according to her specific wishes.

Implications for the Family

When families are discussed in the legal and ethical literature about decision-making, it usually takes place in two rather narrow contexts: childhood and incompetence. The first instance occurs when the patient is a child or minor in the family, fully conscious but considered legally immature. The child is able to make decisions about her wants and desires but lacks the foresight and intuition needed to fully comprehend the implications of decisions and to determine the best direction to take. It is assumed in this case that the family does have this foresight and intuition.

The second instance involves the role of families in surrogate decision-making for incompetent patients. When a patient is comatose or in other ways incapacitated, the family is deemed to possess enough foresight, knowledge of the patient's preferences, and compassion to make the decisions that the patient herself would have made. If no known preferences exist, the family still makes decisions by representing the "best interests" of the patient.[60]

Excepting these two situations, the family retreats into the background and the individual looms as the primary decision-maker within current practices and policy of Western medicine. In actuality, the family may often play an important role in decision-making by providing guidance and advice.[61] This role, though, often goes unnoticed or underutilized by health care practitioners who focus on the patient's permission and consent.

The role of autonomy in Western medical ethics derives from hundreds of years of philosophical orientation towards the individual. This individualistic orientation, coupled with the patients' rights movement and the legalistic atmosphere of consumerism, produced drastic changes in the traditional paternalism of medicine in the last twenty years. The importance of patient autonomy and personal choice greatly increased.

However, many other cultures don't share this new emphasis on autonomy. As an example, Chinese medical ethics offers a glaring contrast to the development of patient-centered medical ethics. The next chapter offers an account of the role of medical ethics and practitioner-patient interactions in Chinese medicine.

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[25] Pellegrino, Edmund, "The Metamorphosis," p. 1159.

[26] Pellegrino, Edmund, "The Metamorphosis," p. 1159.

[27] Pellegrino, Edmund, "The Metamorphosis," p. 1159.

[28] Fabrega, Horacio, Jr., "An Ethnomedical Perspective," p. 608.

[29] Pellegrino, Edmund, "The Metamorphosis," p. 1159.

[30] For more information see Rothman, David J., Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making, (New York: Basic Books, 1991).

[31] Jonsen, Albert, "American Moralism and the Origin of Bioethics in the United States," The Journal of Medicine and Philosophy 16: 113-130. See also Fox, Renee C., "The Evolution of American Bioethics: A Sociological Perspective," Social Science Perspectives on Medical Ethics, ed. George Weisz, (Philadelphia: University of Pennsylvania Press, 1990), pp. 201-217, and Marshall, Patricia, "Anthropology and Bioethics."

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[33] Jonsen, Albert, "American Moralism," p. 125.

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[40] Beauchamp and Childress, Principles , p. 53.

[41] Pellegrino, Edmund, "The Metamorphosis," p. 1160.

[42] Cross, Alan W. and Curchill, Larry R., "Ethical And Cultural Dimensions of Informed Consent," Annals of Internal Medicine 9 (1992): 110-113.

[43] Oken, D, "What to Tell Cancer Patients: A Study of Medical Attitudes," JAMA 175 (1961): 1120-1128.

[44] For more information see Rothman, David J., Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making, (Basic Books, 1991).

[45] Pellegrino, Edmund, "The Metamorphosis," p. 1160. See also Bellah et al., Habits of the Heart, (Berkeley: University of California Press, 1985).

[46] Katz, Jay, The Silent World of Doctor and Patient, (New York: Free Press, 1984), p. 60-62.

[47] Cobbs v. Grant (1972) 104 Cal.Rptr. 505.

[48] Areto v. Avedon, 23 Cal.Rptr.2d 131 (Cal. 1993); See also Truman v. Thomas, Sup., 165 Cal.Rptr 308.

[49] American Medical Association, Current Opinions of the Council on Ethical and Judicial Affairs, (Chicago: AMA, 1989), Sec. 8.08.

[50] American College of Physicians, Ethics Manual, (Philadelphia: American College of Physicians, 1993), p. 9.

[51] Kant, Immanuel, Groundwork of the Metaphysic of Morals [1785], trans. H.J. Paton, (New York: Harper and Row, 1964), p. 96.

[52] Mill, John Stuart, On Liberty [1859], in Collected Works of John Stuart Mill, Vol. XVIII, ed. Robson, J.M., (Toronto: Toronto University Press, 1977), p. 223.

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[54] Callahan, Daniel, "Autonomy: A Moral Good, Not a Moral Obsession," Hastings Center Report, October, 1984, pp. 40-42. See also Veatch, Robert, "Autonomy's Temporary Triumph," Hastings Center Report, October, 1984, pp. and Pellegrino, Edmund, "The Relationship of Autonomy and Integrity in Medical Ethics," Bulletin of the Pan American Health Organization, 24 (4) (1990): 361-371.

[55] Jonsen, Albert, "American Moralism," pp. 128-9.

[56] Pellegrino, Edmund, "The Relationship of Autonomy and Integrity in Medical Ethics," Bulletin of the Pan American Health Organization, 24 (4) (1990): 365-6.

[57] Pellegrino, Edmund, "The Relationship of Autonomy and Integrity," p. 365.

[58] Childress, James, "The Place of Autonomy in Bioethics," Hastings Center Report, Jan/Feb, 1990, p. 15.

[59] Faden, Ruth and Beauchamp, Tom, A History and Theory of Informed Consent, (New York: Oxford University Press, 1986). See also Beauchamp and Childress, Principles.

[60] Veatch, Robert, "Defining the Family's Role in Treatment Decisions," Health Progress, (October, 1986), pp. 50-52.

[61] There may be some historical evidence for increased family involvement in decision making, especially in regard to cost of services. This would have occurred to a larger extent before patient's rights and health insurance became strong factors in medicine.

CHAPTER 3: Chinese Medical Ethics

Traditional Chinese medicine differs from Western medicine in many ways, including its theoretical foundations, methods of diagnosis and treatment, practitioner-patient relations, and the role of the family in medical decisions. However, any attempt to characterize traditional Chinese medicine as a coherent, singular system would be simplistic and ahistorical.[62] The Chinese medical environment consists of a multiplicity of disciplines and divisions, including Buddhists, Taoists, Shamans, Confucianists, Laymen, midwives, etc. And yet, though the Chinese medical system came from a plurality of disciplines and origins, there existed both some universal concepts (the Tao, Yin/Yang dualism, the five elements) and a dominant paradigm (Confucianism) until the introduction and acceptance of Western medicine around the turn of the century. By discussing the common concepts and the dominant paradigm, I will explore the development and foundations of Chinese medical ethics. In particular, I will discuss relations between practitioners and patients in Chinese medicine, including the roles and expectations of practitioners, individuals, and the family.

Before addressing the specific formulations of Confucian doctrine and the roles of the patient, physician, and family, a brief discussion of the common origins and concepts of the diverse Chinese medical system provides a context within which to examine Chinese medical ethics and make comparisons to bioethics.

Common Themes

Most of the philosophical groundwork for Chinese medicine originated in the Late Chou (1121-255 B.C.) and Han (206 B.C.- A.D. 221) Dynasties, with the texts being developed during the Han period.[63] Three concepts pervade these historical texts: the Tao, Yin/Yang dualism, and the five elements.[64]

The concept of the Tao represents an intermingling of heaven and earth which maintains harmony and affects health.[65] The Tao is discussed in conjunction with the two component parts of the universe -- Yin and Yang. Used extensively in the medical literature, the Yin/Yang dualism consists of the fundamental powers which comprise and describe everything from the creation stories to illness.[66] Literally translated, Yang is the sunny side of a hill and Yin is the shady side of a hill. Yet many other meanings of Yang and Yin exist, including light/dark, hot/cold, male/female, good/bad. (There are various theories on Yin/Yang; some divide the meanings further into four or six subcategories.[67]) These forces regulate all that happens -- not only within the universe, but also within each individual. Body organs, and even the inside and outside of the body are associated with either Yin or Yang dominance.[68] The Yin/Yang theory is often misinterpreted as positing that an object has *either* Yin or Yang energy. The original formulation was that the two powers are ever-present and exist in all things.[69]

The five phases are the third common feature in Chinese medicine, though less central than the Yin/Yang dualism. First mentioned between 350-270 BC, the five phases were later incorporated into Confucian political and social ideology.[70] The five elements or phases -- earth, water, fire, metal, wood -- refer to natural substances and phenomena which interconnect through a cycle of subjugation.[71]

These three common themes provide the foundation for the Chinese system of medicine. The balance between the Yin/Yang energies frames the philosophical groundwork for health and disease. Health is an individual fitting into (and balancing within) the larger existence. An upset of this balance is the precipitating event or the cause of illness. "The affinity for Yin and Yang for each other was held to have a decisive influence on one's health. Perfect harmony between the two primogenial elements meant health. Disharmony brought disease and death."[72] When a disruption occurs and disease ensues, it becomes necessary to go to a physician for diagnosis and treatment. The diagnostic and therapeutic approaches attempt to determine the imbalance of energies and correct this imbalance through application of various techniques such as acupuncture and moxibustion.

The Confucian political doctrine greatly affected this notion of health and disease. Confucianism intimately tied health with the maintenance of social order and harmony; the dominant socio-political environment influenced and reinforced the medical system. According to the Confucian doctrine, maintaining a lifestyle in accordance with fixed moral rules contributed to both social harmony and personal well-being.[73]

Confucian Dominance and the History of Chinese Medical Ethics

While there have been many types of medical practitioners throughout Chinese history, a background of Confucianism heavily influenced the intellectual and social discourse. Contemporary medical ethics scholar Ren-Zong Qui states that "traditional Chinese medical ethics is the application of Confucianism in the field of medical care."[74] From a Western framework, Chinese medical ethics can be interpreted as a form of virtue ethics based on cultivating one's compassionate character. There is a strong deontological orientation to these ethics and a physician should follow the duties without regard to consequences.[75]

The history of Chinese medical ethics owes a great deal to the ancient Confucian scholars, as they produced most of the literature considered "medical ethics." In the prefaces to their medical texts, these scholars would provide admonitions, maxims, sayings, and words of advice to other physicians.[76] These informal precepts reflected the authors' personal experiences and principles; they were *not* professional or legal codes.

The first example of literature addressing medical ethics appeared in the seventh century text, Prescriptions Worth a Thousand Pieces of Gold by the physician Sun Simiao. Often called the Chinese Hippocratic Oath, this treatise, entitled "On the Absolute Sincerity of Physicians," delineates three requirements of physicians: first, to develop a sense of compassion and piety; second, to treat every patient on equal grounds; third, to avoid seeking wealth through expertise.[77]

Current Trends

During the last two decades, the number of medical ethics activities has increased dramatically. A conference on Medicine and Philosophy in 1979 in Canton marked the beginning of a period of increasing discussion of issues in medical ethics.[78] By 1980, there was a Chinese journal devoted to medicine and philosophy.[79] During the next few years, Chinese medical ethics concentrated on two issues: euthanasia and discrimination in the provision of medical care. Euthanasia became one of the most discussed topics in medical ethics and sparked numerous radio programs, comments, letters (including one from the wife of former premier Zhou Enlai), and a national conference in 1988.[80] The last decade gave the Chinese medical community a new topic for debate: reproductive technology. Artificial insemination and in vitro fertilization are now widely practiced in China and eleven provinces have sperm banks. In addition, for those couples who choose sex identification of the fetuses, 90 percent of females are aborted.[81] While sex identification is not offered everywhere, these results add to the debate of reproductive technology.

Medical Ethics and the Physician-Patient Relationship

Western bioethics often discusses the physician-patient relationship (perhaps because it forms a large part of Western medicine) and health care providers apply the Western bioethical model to interactions with all patients, including those from different cultures. A look at the physician-patient model of decision-making in traditional Chinese medicine from the practitioner's, the patient's, and the family's viewpoints uncovers some differences and potential conflicts between the Chinese and Western model. In traditional Chinese medicine, the roles of the family and the practitioner are more significant and the individual has less control and fewer "rights" than in the Western model of health care.

Roles of Physicians

The physician-patient relationship in traditional Chinese medicine reflected a paternalism and lack of patient authority and autonomy. Recently, there has been a slight increase in discussion of patients' rights and autonomy, but a strong sense of tradition and paternalism remains today.[82] One practitioner states, "Medicine is applied humanness. To see other people suffer rouses compassion and pity within myself. When the ailing themselves cannot make any decisions, I will make them in their place. I always put myself in their place."[83]

Traditional Chinese physicians seldom discuss the patient's condition -- much less his or her autonomy. Arthur Kleinman, in his discussion of Chinese-style practitioners in Taiwan, describes many physicians who rarely converse with their patients.

> Unless a patient asks, they rarely explain about a cause, pathophysiology, or course of illness. They may not even name the illness. What they do is give the patient detailed prescriptions. For most patients, coming to Chinese-style doctors, that is all that matters.[84]

The reasons for this are two-fold: first, most practitioners believe their patients know very little about Chinese medicine; second, in Chinese culture, the skills of a physician are ascertained by his ability to diagnose an illness from the patient's pulse and a few questions. The best doctors ask nothing.[85] When there is conversation, it is usually only the practitioner who is speaking. In his research, Kleinman noted that the verbal interchange between patient and practitioner was twice as long in Chinese style practitioners' offices than in the Western style ones, but that in the Chinese style, the practitioner asks all the questions because he is the authority.[86]

Inherently a part of this setting, the power differences may add to the therapeutic relationship by providing comfort and confidence in the practitioner. Kleinman notes that power differences are to some extent *expected* by Chinese patients. The practitioner's role is to help with the disease. The patient goes to the practitioner for his special talent, knowledge, or secret remedy.[87] The patient and practitioner rarely communicate about anything except the illness unless they belong to the same social network or have a long-standing relationship.[88]

Families and Individuals in Health Care

Rather than discuss the roles of the family and the individual in traditional Chinese medicine separately, the two should be linked. There is an inextricable bond between family and the individual in Chinese society. As much as the individual is considered an autonomous unit in Western medicine, the family and the individual are intertwined in Chinese medicine. The emphasis of many Chinese values is a sense of duty to one's family, or filial piety. This greatly affects how the medical system integrates the family and the individual into discussions regarding a patient's illness.

Chinese patients rely more on their families during illness and the families willingly participate. Often the family will provide for, take care of, and even make decisions for the patient. While this may seem to be paternalistic in the Western world, it is both expected and provided in the Chinese setting. Let us take, then, this notion of the family making decisions for the patient and try to understand why this happens in Chinese culture.

Family Roles

The family is an essential part of the decision process in Chinese culture. This increased role of the family reflects the Chinese conception of responsibility and interconnection between all the members of a family. The role of the family in Chinese cultures involves three aspects: respect and filial piety, specific family structure, and, perhaps most important, primary responsibility for the patient. Historically, only certain members of a family made decisions. More members of the family now participate in decisions, but the patient is still largely removed from the process. The patient can express opinions, but the family makes the decision.[89]

"The family is seen as a model of society... a duty-oriented model, in which each member has his or her own role responsibilities."[90] The family has a very important role in decision-making because they, too, will be affected by any decisions regarding treatment (e.g. bad luck to the family, etc.). The role of the family assumes paramount importance out of deference to cultural and ancestral obligation.

In pre-modern China, members of the family made decisions based on the specific family structure, with a patient's degree of autonomy determined by his or her age and status in the family and by the family's degree of modernity.[91] Confucianism reinforced a notion of total subservience to the wishes of the father.[92] Fathers and husbands predominantly made decisions. Women deferred to their fathers, then husbands (when married), and, finally, their sons (after the death of their husband).[93]

However, after 1949, patriarchal authority started to decline. Qui states that currently, "Decisions involving the family need to be made by all the members of the family after consultation, not by any one individual."[94] Still the decision is made by the *family*, after consulting the physician and the patient. The patient's opinion is considered, "but [it] is not considered to be an exercise of his or her right to self-determination."[95]

Finally, the family is seen as the one with *primary* responsibility for the care of the severely ill patient.[96] This view is held not only by the family and patient, but by most traditional Chinese doctors. Arthur Kleinman, in his discussion of healer/patient/family interactions notes, "Chinese-style physicians... view patients or families as most responsible for minor problems, but families alone are regarded as the locus of responsibility for serious medical problems." [97]

Considering this extensive network of familial relations and familial responsibilities, the family's role in decision-making retains tremendous importance. This expected and revered role of the family demands understanding, if not respect, from other cultures.

Individuals and Patients

In Chinese culture, the patient assumes an entirely different role from patients in the Western model. Often, the patient is not given the power of individual autonomy, such as knowing the diagnosis and making treatment decisions, because it is not thought to be therapeutic or necessary for her to know. Though there has recently been more discussion of patient self-determination, a "rights-oriented individualism is essentially alien to the Chinese."[98] While this may be changing with the influx of Western medicine in Chinese cultures and with increased attention to American medical ethics, family decision-making for the patient still seems to be the norm rather than the exception.

The main reason given for the family not wanting to disclose information to the patient concerns the potential worsening of the patient's condition. Since the patient is already sick, burdening her with more information about the diagnosis or asking her to make decisions regarding treatment options would cause undue suffering that could otherwise be avoided.[99] It is often believed that "the patient only needs repose,"[100] and that too many questions will exhaust and confuse the patient.

This suffering comes from actually naming the disease,[101] a belief found in other cultures as well (Japanese,[102,103] Italian,[104] Arabic[105]). The "naming" of a disease brings bad luck to the patient, an invitation for the disease to actually cause death. "Acknowledging an impending death is like casting a death curse upon the person; it will make the person despair and die even sooner."[106]

In addition, if a physician were to reveal the terminal nature of an illness, it would be tantamount to revealing that there is no hope. "It tells patients that their physicians have given up on them and they might as well give up, too."[107] Only a terribly rude and unthinking physician would commit such a grievous error. The physician would not only be hastening death, but would be displaying the most hideous and disrespectful demeanor in dealing with a patient.

Furthermore, as indicated above, the physician may only discuss the patient's condition with the family members, especially if the condition is serious. The patient may, in fact, agree to this interaction and this lack of information because it is expected:

> [Practitioners] tell the family, not the patient, that he is suffering from

> cancer or that the treatment of a serious illness has been unsuccessful. This is viewed neither by patients or by practitioners as an ethical dilemma. Since the family, not the patient, commonly makes crucial decisions, the patient does not see himself as needing such information.[108]

A family's efforts to hide the diagnosis from the patient derives from a concern for the well-being of the patient. They try to withhold such information in order to alleviate some of the patient's suffering. While this approach seems reasonable, it may produce conflict when Western physicians and other health care providers follow their own moral standards of upholding patient autonomy in such a setting. Western practitioners may see the family as interfering with the individual's right to choose the course of their care and to finish their lives with an expectation and acceptance of the prognosticated outcome. The family, though, doesn't conceive of a patient having a "right" to choose. Their model of patient care is not based on "rights;" theirs is a "sociocentric" model which realizes the inextricable connection between family and the individual. When personal responsibility is intrinsically linked with familial responsibility, it seems simplistic to disregard the power dynamics and expectations of a Chinese family within the Western health care model.

The roles of the practitioner, patient, and family in Western and Chinese medicine vastly differ. In order to further understand the context of decision-making, a discussion of how Western and Chinese (or Non-Western) cultures conceptualize the "person" would illuminate some of the problems of comparing decision-making practices between cultures. For instance, if cultures differ in their concept of "personhood," then the Western principle of autonomy might not only be inapplicable to Chinese patients because they refuse it, but it may also be incomprehensible. If autonomy refers to a Western conception of a person and the Chinese medical culture doesn't share that conception, discussing autonomy would be fruitless. The concept of autonomy may be *explainable* to Chinese patients, but they may disagree with its foundations and, therefore, not accept it as a principle which they should follow.

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[94] Qui, Ren-Zong, "Medical Ethics and Chinese Culture," p. 171.

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[96] Kleinman, Arthur, Patients and Healers, p. 309.

[97] Kleinman, Arthur, Patients and Healers, p. 285.

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[99] Muller, Jessica H. and Desmond, Brian, "Ethical Dilemmas" p. 325.

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CHAPTER 4: Differing Conceptions of "Personhood"

Any project which addresses the way in which individuals make decisions must discuss how the individual views herself within a society. How a person defines the "self" will affect how actions or decisions arise. For example, if a person makes a decision without consulting anyone else, it may be assumed that the person holds certain conceptions about his or her "self" in relation to making this decision, e.g. that only the preferences and views of the one individual are important in making this decision. The conception of a "self" or "person" within a society or culture profoundly affects any discussion of rights, responsibilities, and, for our purposes, decisions and medical care.

Conflicts produced by these varying conceptions of the person will frame how to approach conflicts between cultural systems. Specifically, this project will help to resolve the case scenario presented in Chapter 1 in which there may be conflicting cultural systems *within* a single society. (When I refer to a single society, I refer to the medical, legal and social structure wherein these interactions occur, e.g. a U.S. county hospital serving a large immigrant population.) When groups conflict in a situation where one culture has social or political dominance, the norms of the dominant culture are likely to take precedence.

Are there are differences between the Western and the Chinese (or non-Western) conception of self? If differing conceptions of self exist, how does this bear on a situation in which decision-making norms conflict? The remainder of this chapter addresses the former question while the following chapter discusses the latter.

The discussion of selfhood begins by defining the concepts of self and personhood and moves to an examination of the historical development of personhood in societies as reflected in their social, religious, and legislative institutions. However, the chapter must be prefaced by noting that the developments of concept of the person are merely trends or generalities within extremely complex societies. To consider these as finite and defining representations of these societies fails to consider the variability and diversity of individuals responding to numerous situations, stimuli, philosophical systems, etc. Indeed, it has been argued that the diversity *within* cultures is greater than any diversity found between cultures.[109] While I agree that to rigidly characterize these types of societies might be dangerous, some value derives from noting these as possibilities or guiding norms. As such, they help to frame the analysis of situations arising in a setting of conflicting cultural norms. Constructing a situation of cross-cultural conflict, though this type of conflict may arise within cultures as well, posits the difficulties more clearly and distinctly.

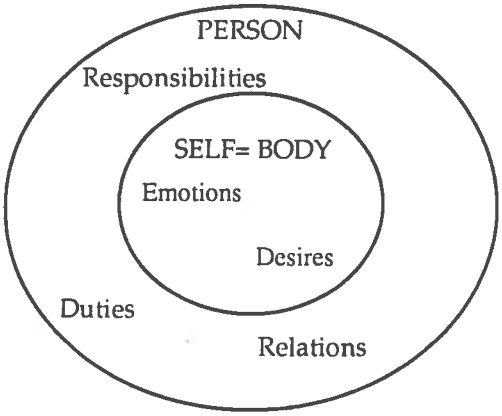
Distinction Between "Self" and "Person"

The literature of psychological anthropology distinguishes between the concepts of "self" and "person." Mauss' pivotal essay entitled A Category of the Human Mind initially explores the definitions of self and person in relation to the awareness of the linguistic "me" (*moi*) as distinct from the "role" and "person" (*personne*). "Self" describes the biological organism itself and the "individual awareness of a unique identity;"[110] it is a body ("me") which is separate from other living things.

In contrast, the notion of a "person" reflects a social concept of humans. A conglomeration of rights, responsibilities, and a complex tangle of relationships, "the 'person' is society's confirmation of social significance."[111] The term "person" takes the empirical reality of the biologic organism (the "self") and ascribes certain social features, relationships, and interconnections to its existence. Non-Western societies tend to conceptualize the "self" and "person" as two distinct entities. The distinction between "self" and "person" for Western society is less discernible. Members of Western society identify the person *as* the biological organism itself, not as an extended conception of relations and responsibilities.

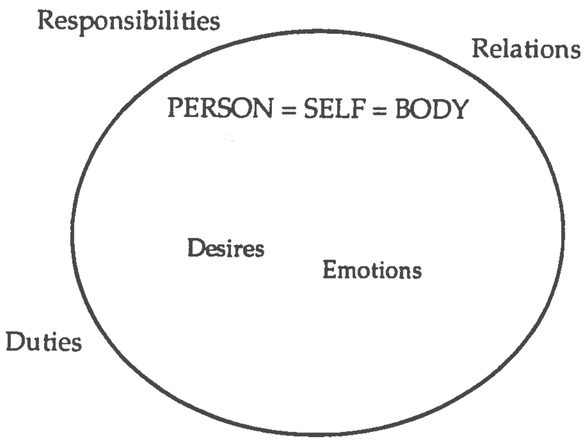
The distinction can be understood visually, though simplistically, with concentric circles representing the Western and non-Western versions of the person. In the non-Western View (Figure 1), the self is represented by the inner circle. The person is a larger circle of relations and responsibilities that may involve other entities such as communities and other selves.

Figure 1



The Western view of the self and person doesn't distinguish between the biological self and the person. The Western view identifies those connections with the biological entity itself, not as part of some larger conception of the person (Figure 2).

Figure 2



Western and Non-Western Conceptions of the Self

Few scholars question the claim that the Western conception of the self differs from most others. This distinction lies in the way in which the members of a society view themselves in relation to each other and to the larger society. The Western view idealizes the individual member of a society while the non-Western position reflects interconnection and collectivism.

Dumont states that two kinds of societies exist: those in which individualism reigns supreme,[112] and those in which "the paramount value lies in society as a whole."[113] For the former society, the individual's value is "absolute; there is nothing over and above his legitimate demands."[114] "Ontologically, the society no longer exists."[115] For the holist society, "the stress is placed on the society as a whole, as collective man."[116]

Shweder and Bourne characterize the distinction as one between an egocentric orientation, where "society is imagined to have been created to serve the interests of some idealized autonomous, abstract individual existing free of society yet living in society,"[117] and a sociocentric one where the collective interests of a society require the subordination of individual interests.

In the same vein, Kirkpatrick and White designate the psychological formulation of the two types of societies as singular and collective -- a contrast between the Western view that "all psychological matters pertain to the single person"[118] and a non-Western view in which family and community also play a role in the psychological construction of the person. Other scholars such as Sampson,[119] Marsella,[120] and Hsu[121] postulate similar distinctions between the Western and non-Western conception of the person.

Historical Development of Western "Person"

I suggest that the Western and non-Western conceptions of the person exist on a continuum, with fully isolated persons and completely interconnected persons at either extreme. While conceptions of "person" have evolved from common origins, certain influential thinkers and events helped reformulate the Western development of the "Self as Person."[122] Beginning with the Greeks and Romans and continuing with the rise of Christianity, the Renaissance, and later, Calvinism, the concept of a more definable and isolated person evolved. This historical perspective is important because these psychological trends have shaped the current Western systems and governments and led to the institution of the individual in Western, and particularly American, society.[123]

The Moral Conscience and the Rights of the Person

Greek moralists provided an essential dimension to the conception of the person: the moral conscience. The moral person used reason or self-mastery[124] and possessed "a sense of being conscious, independent, autonomous, free, and responsible."[125] It was this sense of the moral person which was translated into law as obligations and rights. Plato and Aristotle spoke of self-sufficiency of the polis which "becomes an attribute of the individual that is either assumed as a fact or posited as an ideal by the Epicureans, Cynics, and Stoics."[126]

Mauss suggests that the modern term, "person," derives from the Latin "persona," or mask. He argues that this word -- originally related to the ceremonial mask, ancestral mask, and ritual mask -- began to change meanings somewhat during the Greek and Roman civilizations. It became "a basic fact of law"[127] that when the members of society began to have their own civil personas or masks, they gained rights within the society. Mauss states that the revolt of the Plebs to gain full citizenship in the Roman society was a landmark in this transition.[128] Each member of the society (excepting women, slaves, and others) became a separate and equal constituent in the civil sense; the civil mask was a "right" within the society.

Christianity and the Renaissance

The notion of individualism as a value in itself came from these beginnings and matured with the development of Christianity. (Indeed, Dumont argues that Christianity could not have been so successful had it not offered some value of individualism, because the notion permeated Hellenistic thought.) The Christians added more to the sense of the person through their concept of the soul. The teachings of Christ adhered to a notion of Man as an individual in relation to God. "The individual soul receives eternal value from its filial relationship with God."[129] This value, however, is "outworldly," not relying on the earthly existence. With time, this focus on the individual changed to include a more earthly value of individualism. Dumont attributes this change in scope to the 8th century establishment of Papal power in the West. This "fundamental ideological shift" established the Church with power to rule over the world, directly or indirectly.[130] What was once the outworldly formulation of the Christian teaching (each soul as individual in relation to God) soon became a distinct tie to the tangible world. "The Christian individual [was] now committed to the world in an unprecedented degree."[131]

In the Renaissance, reason and the centrality of humankind became the dominant model. This further focused actions and responsibility on the individual. Each person could use reason to reflect upon potential actions. Descartes postulated that reason allows one to control the passions. "The true function of reason, then, in the conduct of life is to consider without passion all perfections of the body and soul that can be acquired by our conduct."[132]

This commitment to the world and the further reinforcement of individualism as the preeminent characteristic was galvanized with the Calvinist and Puritan teachings. While the Enlightenment and the Reformation aided the process, Dumont (drawing on the work of sociological historian Ernst Troeltsch) views Calvinism as the last stage of the process toward unbounded individualism. The dichotomy between the worldly self and the outworldly individual-in-relation-to-God "disappeared" in Calvinist doctrine. This occurred as Calvinism posited the predestination of all beings. In this way Calvinism rejected, in much the same way as Luther, redemption through the Church and through good works. Those who were predestined were to work for the glory of God in the world as proof of their selection. Calvin maintained that the Church should control political life as well as "regulat[e] all activities within the social community as a whole."[133] With this movement, he committed the individual to this world and adapted individualism to this, more tangible, world.

Individualism assumed ultimate importance. The concept of the individual became synonymous with the concept of the person. From the above definition of person as the conglomeration of social relations and responsibilities of any being or self, I posit that the notion of "person" in Western society came to mean "individual" with the limits of one's responsibilities and relations being defined by the physical boundaries of the self.

I would suggest that as this individualism gained acceptance in North America through the influence of those settlers devoted to Calvinist teachings, certain secular aspects of it, including that of individual consent, were implanted in the identity of North Americans.[134] Reinforced by philosophical developments from the Enlightenment onward and framed by a mistrust for government involvement in religious organizations, the individualism that flourished in early American society and that was encoded into the democratic and legislative structures was profound. This individualism, however, did not reflect a church or religious influence. Rather, this Western conception of the self showed a belief in the power of rational beings and accounts for the increase in personal liberty and autonomy as outlined in the U.S. Constitution and Bill of Rights.

Chinese Conceptions of the Person

The Chinese conception of the person is characterized by a reliance on interpersonal relationships much more than the Western concept of person.[135] This is best thought of in terms of the Chinese word *jen*, or an individual's transactions with his fellow human beings. The concept of jen views man in terms of a larger whole that places him in a web of interpersonal relationships which involves parents, siblings, and close relatives.[136] It is a dynamic equilibrium which involves cultural heritage and which provides a strong sense of identity and fulfillment. The traditional Chinese view of personhood relies almost exclusively on this interconnected framework. "Outside the relational context of the significant others, there was very little independent self left for the Chinese."[137]

In Kleinman's description of patients and healers, he presents examples of the family as a very important element in making decisions for the patient. This larger conception of the decision-making unit gives some insight into the Chinese conception of self. Not a fully autonomous unit which always decides for itself, the "self" is one unit within the larger context of family and must be considered within this larger sphere.

Mauss also describes the Chinese conception of self as one with many interconnected elements. He discusses the *ming*, or name, as "represent[ing] a collective noun"[138] stemming from one's ancestral origins and being passed on to one's descendants. The concept of person also includes a temporal link through time from one's ancestors, through the self, to one's descendants.

Mark Elvin accepts Mauss' categorization of the name as possibly reflecting a Confucian formulation of the person as center of a "multiplicity of specifically defined relationships."[139] He argues, though, that as a blanket categorization of the conception of person within Chinese society, it is inaccurate because other compelling views existed in which the concept of person defined a more individual and independent unit. He concludes his convincing piece by stating that the conceptions of person within Chinese society were "extraordinarily varied."

The variations of the Chinese concept of self are still changing. Godwin Chu notes that in China after the Cultural Revolution, contemporary concepts of the person have become far more independent and assertive. This is shown in the public criticism of government, published criticisms of public policy in the *People's Daily*, and a general decrease in the authority of the family structure.[140]

While these are generalizations, the conceptions of Chinese "personhood" nonetheless provide a useful base from which to explore differences between individualism and one of many alternative frames of reference.

Implications of Individualism for the U.S. Health Care System

The medical structures of individualism in place in the U.S. reinforce the cultural model of the person as isolated and individual. The health care arena has only recently introduced structures and systems which represent the individualism of the Western sociopolitical framework. These include informed consent laws, a patient "Bill of Rights" and court cases which strengthen the individual's position.

This role of the individual in medical decisions has evolved only in the past few decades (See Chapter 2). The current value placed on individual freedom and self-determination isn't represented in the medical literature until the early seventies. Most of this literature specifically referred to experimentation, and not to standard medical care.[141] The principles of patient autonomy and informed consent for medical care were reflected in the American Hospital Association's "Patient Bill of Rights" in 1974.[142] In 1991, Congress passed the Patient Self-Determination Act which requires health care facilities to ask patients about living wills or Durable Powers of Attorney for Health Care, and to provide information on these documents.

I would suggest that the discussions of autonomy and the mechanisms installed to protect it (eg. informed consent) are indications that the Western medical model is finally beginning to espouse the individualism so dominant in society. While there have been recent articles and court decisions which have questioned the dominant position of autonomy,[143] most scholars argue that autonomy still is one of the most important values

-- if not *the* most important value that the U.S., as a society, holds.[144]

There are some, though, who question the concept of the Western person as applied to medical decisions. One of these dissenters, Edmund Pellegrino, questions the notion of autonomy and its insistence on the separation of the individual from her other relations. Autonomy fails to account for the fact that humans are members of a moral community with other commitments, interests and obligations.[145]

Eric Parens, fellow at the Hastings Center, states that the current Western conception of the rational powers of the individual neglects the other aspects of decision-making that are perhaps less predictable but no less a part of decisions. These include the passions and fears of the patients, the fact that patients may not want to know the truth all the time, the potential of patients not wanting to be "in control," and the interplay of family and other relationships for a "Western" patient. Parens states that the current Western conception of the person needs to address a richer conception of the self that would "keep in play the difficulties that are our passions, our sometime inability to face truth, our ultimate inability to bring death under control, and our dependency on others."[146]

Different Selves Within One Culture

Different cultures vary in their conceptions of the self and person. I have shown how many scholars argue that the Western conception of the person is one of individualism within a loosely organized society. Under this model, society was created to further the reasonable interests of the individual. The non-Western conception reflects more of an interweaving of responsibilities and relations between members of a society. This may include family structures, kinship roles, or community values. In each case, these non-Western conceptions employ a notion of personhood in which the boundary between the self and the rest of society remains "at best fuzzy."[147]

Returning to our original scenario of a Chinese woman whose family asks that she not be told her diagnosis and that the family be asked for consent instead of the patient, we consider the conflict between the Western view of the situation and the Chinese approach. Viewed within the context of the preceding chapter, it becomes clear that the questions Western medicine asks patients reflect the Western assumptions about personhood. The system that requires a decision -- in this case, a decision concerning hospital policies -- may assume the following are straightforward questions: Do you want to be told if you have a terminal diagnosis? Do you want CPR if it is needed? Do you want any advanced directives?

These questions may ask for impossible answers, or answers that one person in the family may not be able to give. For instance, if the patient comes from an interconnected Chinese family system, asking the person about what treatments she wants may not even be a question she understands. She may fail to understand because the medical system she is accustomed to does not ask such questions of its patients; the questions are a surprise. Perhaps more significant in the context of our discussion is the possibility that the patient may not understand because such decisions would affect far greater interests (family and community, as well) than the patient feels comfortable answering for.

In addition, the patient's understanding of her place in the family/culture might require, as in the test case, that the family members step in and serve as mediators between the health care team and the patient, making decisions and filtering information. While this may be a reflection of the values and goals of the patient's particular cultural system, the health care system might view this as a violation of its duty to inform the patient and conduct these medical discussions with the patient herself.

If these differing conceptions do exist, can conflicts which are based on different cultural conceptions be resolved? Should one conception of the person "trump" the other because it represents the legislative and philosophical orientation of the dominant culture? Should the representatives from the non-dominant culture (the patient and family in this context) be allowed to act according to their own cultural values when these do not coincide with the established views of the society in which they live? These questions about tolerance and moral relativism will be addressed in the following chapter as the discussion approaches a workable compromise to these cultural conflicts.

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[110] La Fontaine, JS, "Person and Individual: Some Anthropological Reflections," The Category of the Person, eds. Carrithers, Collins, and Lukes, (Cambridge: Cambridge University Press, 1985), p. 124.

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[113] Dumont, Louis, "A Modified View," p. 94.

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[115] Dumont, Louis, Homo Hierarchicus, p. 8.

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[121] Hsu, F.L. K., "The Self in Cross-cultural Perspective," Culture and Self: Asian and Western

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Perspectives, eds. Marsella et al. (New York, Tavistock, 1985) pp. 24-55.

[122] If interested in such a perspective, I recommend Charles Taylor's Sources of the Self, (Cambridge, MA: Harvard University Press, 1989).

[123] Taylor, Charles, Sources of the Self, (Cambridge, MA: Harvard University Press, 1989), p. 12.

[124] Taylor, Charles, Sources of the Self, p. 115-126.

[125] Mauss, Marcel, "A Category of the Human Mind: The Notion of Person; The Notion of Self," The Category of the Person, eds. Carrithers, Collins, and Lukes, (Cambridge: Cambridge University press, 1985), p. 18.

[126] Dumont, Louis, "A Modified View," p. 96.

[127] Mauss, Marcel, "A Category of the Human Mind," p. 14.

[128] Mauss, Marcel, "A Category of the Human Mind," p. 16.

[129] Dumont, Louis, "A Modified View," p. 98.

[130] Dumont, Louis, "A Modified View," p. 112.

[131] Dumont, Louis, "A Modified View," p. 113.

[132] Taylor, Charles, Sources of the Self, p. 151.

[133] Dumont, Louis, "A Modified View," p. 117.

[134] Taylor, Charles, Sources of the Self, p. 194-5, 227-230.

[135] Hsu, F.L. K., "The Self in Cross-cultural Perspective." See also Chu, Godwin C., "The Changing Concept of Self."

[136] Hsu, F.L. K., "The Self in Cross-cultural Perspective," p. 32-36.

[137] Chu, Godwin C., "The Changing Concept of Self," p. 258.

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[139] Elvin, Mark, "Between Earth and Heaven: Conceptions of the Self in China," The Category of the Person, eds. Carrithers, Collins, and Lukes, (Cambridge: Cambridge University press, 1985), p. 157.

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CHAPTER 5: Conflicts Between "Persons" -- Relativism

An examination of cultural and moral relativism helps the discussion of conflicting values and the search for universal standards. Cultural relativism holds that cultures employ culture-specific conceptual frameworks which affect how the members of the culture perceive ethical dilemmas, cultural norms, fact claims, etc. This notion of cultural relativism encompasses two different facets of relativism: cognitive and moral. Cognitive relativism holds that all truth and knowledge are relative to specific cultures. Moral relativism claims that an action is morally right only in reference to a particular moral code; there is no universal moral code. These forms of relativism led many to believe that the views of other cultures should therefore be tolerated and respected.

Certain aspects of relativism and tolerance have been questioned. Cognitive relativism has been discounted by philosophers as internally inconsistent. In addition, while moral relativism has not itself been discounted, the notion that all actions of others should be tolerated because of moral relativism, has also been questioned.

The notion of tolerance, however, must be seen from the historical context in which it was developed. Relativism and tolerance emerged from a time in which non-white races were believed to be progressing towards an evolutionarily advanced Western model. After considering briefly the historical and anthropological development of cultural relativism and tolerance, I will address the philosophical arguments against cognitive relativism, the "truth" in moral relativism, and the arguments against a view of generalized tolerance based on moral relativism.

Cultural Relativism

The theory of relativism developed and evolved over the past hundred years as a result of increased anthropological study of different cultures. This form of relativism -- descriptive relativism -- holds that since cultural models form all social and psychological characteristics, the variability of these characteristics depends on cultural variability. Developed by anthropologists in the 19th century, this view holds that all characteristics depend on the culture in which they were formed and within which they function. However, the anthropologists who espoused these views also held that cultural diversity merely represented differing stages in their "unilineal stage theory of social and cultural evolution."[148] Their theory suggested that Victorian culture was the most advanced.

Normative relativism emerged during the 20th century, with the work of Boas and Herskovits. They added to descriptive relativism a conclusion regarding the value, or possibility, of judgments about other cultures. The normative relativists claimed that "because all standards are culturally constituted, there are no available *trans*cultural standards by which different cultures might be judged on a scale of merit or worth."[149] This claim also applies to generalizations of all cultures and the lack of "*pan*cultural" standards.

Normative relativists regarded both cognitive (descriptive) and moral (evaluative) propositions in this manner. Cognitive propositions contain true-false claims (e.g. loud noises cause cancer) and moral propositions contain right-wrong claims (e.g. killing is wrong). Normative relativists stated that "truth claims of descriptive propositions are relative to the cognitive standards of the cultures in which they are embedded."[150] Further, the claims of ethical propositions reflect the moral standards of the originating culture and there are no universally acceptable standards by which to judge different ethical claims of right and wrong.

Normative Relativism and Tolerance

Of primary importance to normative relativism is the notion of tolerance and its historical basis. The argument for tolerance proceeds as follows: Since there are no universal standards by which to judge the inherent value of any moral framework (whether it is "more right or wrong" with respect to other frameworks), "the only valid normative judgment that can be made about them is that all are of equal worth."[151] Though greatly debated by both philosophers and anthropologists, this notion of tolerance arose in a period which marked an improvement from the Victorian attempt to Westernize and convert those societies dominated through colonization.

Normative relativism, and the call for tolerance that grew from it, arose out of the pessimism of the late nineteenth and early twentieth centuries in the United States. "The confidence in the moral integrity, wisdom and justice of the political order was severely eroded"[152] through ethnic strife, class conflict, and a questionable economic future. The Western world began to question the supremacy of industrialization, and this growing concern fueled the fires of relativism. As Elvin Hatch summarizes:

> Relativism was another manifestation of the skepticism and pessimism that was growing in America. Relativism denies the social, moral, and intellectual preeminence of Western society: it asserts that our own values, beliefs, and institutions cannot be shown to be better, and that the principle which underlies our position vis-a-vis other societies is the principle of equality.[153]

Relativism grew out of the work of Franz Boas, a noted anthropologist at the turn of the century, who assaulted the theory of unilineal cultural evolution towards Western society. Through his students and followers, the relativism movement reached its "classic" stage as the central tenet of the anthropological profession in the United States in the 1920s.[154] Expressed through the work of Boas, Ruth Benedict and Melville Herskovits, cultural relativism espoused two points: first, all cultures are equally valuable; second, non-white races are as able as any other to acquire technically more complex cultures.[155]

Cognitive Relativism Questioned

Cognitive relativism, a central tenet of cultural relativism, has been discounted by the philosophic community as being internally inconsistent. Cognitive relativism holds that truth and knowledge are only applicable within a particular conceptual scheme. This view, that a given statement is true only in the framework in which it was formed, fails to surmount its self-contradictory claims.

The argument proceeds that if the cognitive relativist believes that each statement is at most relatively true for a given conceptual framework and is not absolutely true, then the relativist's statement contradicts the thesis itself. If it is applicable to itself then the relativist's position that all statements are relatively true is *itself* only "relative" or "subjective" and therefore only believable by those who share the relativist's framework. If, however, the relativist's position is itself not applicable to her own thesis, then she posits the existence of an absolute truth and therefore contradicts her own thesis.[156]

Chris Swoyer allows some possible merit in cognitive relativism, the existence of differing, though not contradictory, conceptions of the truth.[157] He does this by attacking a certain aspect of cognitive relativism. He states that the notion of truth held by cognitive relativists often takes the form of the statement: a statement may be true for Jones but false for Smith. Swoyer attacks what he calls this "strong" view of relative truth because, in referring to true-for-one and false-for-another, the relativist relies upon absolutist notions of truth. He states that if a statement is true in one conceptual framework and nonexistent in another, then the two frameworks may indeed be different and translation between them impossible. To then say that a statement is true for one and false for another is inapplicable. Rather, he supports a "weak" view of relative truth which states that a conception can be true in one framework and inexpressible (and hence neither true nor false) in another. In supporting a weak version of cognitive relativism, Swoyer still acknowledges the possibility of alternative conceptual frameworks.

Moral Relativism Affirmed

Much in the same way that Swoyer supports some aspects of cognitive relativism, Bernard Williams posits some claims about moral relativism. In his essay, "The Truth in Relativism," Williams states that given two systems of belief that are exclusive of one another, there are two types of confrontations between them: real and notional. Real confrontations are those in which it is possible for members of a system of belief S1 which do not hold a belief A, to change beliefs or hold the belief about A that S2 holds without losing their sense of reality. On the other hand, notional confrontations are those in which at least one set of beliefs in S2 does not present a real option for people with S1 beliefs. For it to be a real option for them -- one whose terms and basic premises they at least understand -- they would have to severely change their understanding of reality.[158]

Williams states that when there are real confrontations between belief systems, those in conflict will employ some vocabulary of appraisal, right-wrong claims, true-false claims, etc. However, when in notional confrontation, the vocabulary of appraisal is not applicable. A notional confrontation lacks any relations that would make an appraisal worthwhile.

His relativism holds that when two Ss stand in notional confrontation with each other, questions of appraisal do not genuinely arise. This, he claims, is the "truth" in moral relativism: the existence of differing moral codes in which values cannot be reconciled.

Tolerance Questioned

Tolerance arose from normative relativism's claim of differing cognitive and moral standards of different cultures. It was favored in a time of pessimism about the future and continued oppression of Non-Western cultures. The notion that relativism produces tolerance is currently criticized from both philosophical and anthropological fields.

World events and philosophical insight questioned the call for blanket tolerance. World War II provided a prime example of conflict between cultural values. Nazism and the views of German racial superiority led to some of the most universally repugnant policies and actions of the modern era. The war became a symbol of conflict between the values of tyranny and aggression vs. democracy and freedom. Anthropologist Elgin Williams exemplified the growing disaffection with relativism in his strong criticism of Ruth Benedict and ethical relativism in the post-war era.[159] He questioned whether Americans, so rapidly educated in the result of cultural differences during the war, would accept Hitler's culture as equally valid as their own.

Tolerance may be justifiable, some claim, but this justification must appeal to a universal such as respect for all persons.[160] This, of course, still appeals to a Western notion of the value of persons.

Philosophical Arguments

The strongest critique of tolerance based on relativism assails the logical progression from the existence of a diversity of moral views to a blanket acceptance of these views. The argument for tolerance proceeds as follows: Since the term "right" means "right for a given society," it is therefore wrong to condemn another society or interfere with the values or behavior of that society. Williams claims that this form of relativism, "vulgar relativism," contradicts itself by stating initially that all uses of right and wrong are subjective and then stating that tolerance is right in a non-subjective way. The argument is self-contradictory.

Anthropologist Elvin Hatch outlines a similar argument. He states that the description of the empirical state of affairs -- variability in moral codes -- does not logically require that cultures *ought* to accept each others' moral codes as equally valid. The transition from an "is" statement to an "ought" involves a questionable assumption of the value in every occurrence. "The fact of moral diversity no more compels our approval of other ways of life than the existence of cancer compels us to value ill-health."[161]

Universals in Moral Codes

The notion of universal values resurged at the end of the war. The period of optimism and the rejection of tolerance in the wake of Nazism led many to believe that universal values or a "psychic unity" of humankind could be found. While many attempted to arrive at universal norms or values by which to judge different value systems, or to unite mankind, there were still variations in interpretation of these universals, due to either factual belief differences, or social vs. psychological interpretations. Recent work has attempted to outline universals while keeping in mind fundamental differences between cultures.

Hatch proposes a universal principle for judging the adequacy of values. He describes the "humanistic principle:" the well-being of people ought to be respected. It is right to treat people well, and it is wrong to harm them.[162] He assumes, however, that this is not a culture-bound idea, though it is inherently value-laden with the concepts of harm and beneficence.

He continues with a recognition and discussion of those cultural values that fall *outside* the realm of this humanistic principle. These include "sexual mores, marriage patterns, kinship relations,... forms of etiquette, conceptions of deity, and others."[163] Often intertwined with the humanistic standard, these values must be looked upon with the eye of relativism; no universal norm can be applied to them.

He offers Western health care as an example of a system based on the humanistic standard because it deals with the universal principle of helping people. He acknowledges, though, that the system is influenced by many factors that are certainly not universal. These include cultural conceptions of the rigid social hierarchy between physicians and nurses, a keen emphasis on legal safeguards, and the notion of the autonomy of the patient.

Richard Shweder also postulates some universals in moral codes, but highlights the ultimate differences between them. First, some moral codes are alike in that a transgression of the code triggers an emotional response. Repugnance, shame, anger, and indignation may indicate a universal aim of moral codes -- "to preserve and enhance the spiritual dignity of persons."[164] Secondly, social practices and institutions universally appeal to "natural laws" or objective obligations within these societies (natural law in the Bill of Rights, duties of Hindu dharma, the ten commandments, etc.). Thirdly, there is a universal idea of justice -- the conception that like conditions require similar moral judgments. Fourthly, there are universally morally repugnant actions, such as brother-sister incest, fathers making and then breaking promises to sons, etc. Finally, certain virtues seem to be upheld across cultures. These include "the keeping of promises, protection of the vulnerable, fair allocation, taboo on incest, [and] reciprocity-gratitude."[165]

In light of these universals, Shweder insists that much of decision-making refers not to universals but to the specifics of a culture.

> The main idea is that any moral decision is the product of a line of reasoning involving principles and concepts, some of which are universally distributed and many of which are not. Not everything that is rational or reasonable is universal.[166]

He outlines six culture-specific, or discretionary, features of moral codes. First, the code can be grounded on a conception of natural law based on "rights," "duties," "ends," or on the "good." Second, there is a fundamental unit of moral discourse that may center on the individual, or on the social role or status attributed to that person and the attendant social parts to be played. Third, cultures vary in their designation of the moral agents. (Shweder gives the various examples of moral agents: business corporations, fetuses, or members of the family but not outsiders.) Fourth, moral codes vary with respect to boundaries drawn (symbolic, psychological, and physical) around the self. For example, honor and reputation are sometimes considered more important than life itself; sometimes they aren't. Fifth, the universal principle of justice does not provide structure for interpretation of which dilemmas are similar and which are different. For example, "it is wrong to eat dogs" and "it is wrong to eat cows" are both similar and different statements open to interpretation. A reference to justice in which similar situations are treated in similar ways doesn't help if both are animals and yet one is considered sacred. The final discretionary aspect of moral codes is the choice of how to represent the natural law. It may be believed to come from divine command, sacred texts, or may be "individual" and accessible to any average adult.

Conclusion

Based on the arguments above, tolerance does not necessarily proceed from moral relativism. While tolerance may come from universal claims -- for instance, a respect for humanity or the ultimate dignity of other cultures -- it cannot be justified by arguments from relativism. The arguments for tolerance from relativism draw upon universal claims while stating that all values are relative.

Relativism, both cognitive and moral, does provide certain insights. The truth in moral relativism stems from a realization that different cultures can hold different value systems and that these value systems may be incomprehensible to the other. Conflicts in moral value between these systems in are not "real conflicts" in the sense that they cannot be resolved or even argued without one party losing its sense of reality. Different cultures maintain different psychological frameworks which may appeal to different cognitive (descriptive) views of the world or different normative (moral) views.

After WWII, many realized that a universal acceptance of all cultures could lead to gross abuses of human rights, and led some to argue for universal principles that would lead to a "psychic unity" for all of humankind. The notion, though remarkably productive in drawing similarities across cultures, inadequately addresses those features of cultures which clearly fall beyond the scope of moral universals.

The notion of relativism remains paramount within the context of the next chapters. The test case illustrates conflict between two cultural systems and questions whether the values in health care are based on universal principles of beneficence and good patient care, or on individual cultural definitions not amenable to cross-cultural reference or discussion. If those pluralism and American society.

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[148] Spiro, Melford, "Cultural Relativism and the Future of Anthropology," Cultural Anthropology 1: 259-286.

[149] Spiro, Melford, "Cultural Relativism and the Future of Anthropology," p. 260 [his emphasis].

[150] Spiro, Melford, "Cultural Relativism and the Future of Anthropology," p. 260.

[151] Spiro, Melford, "Cultural Relativism and the Future of Anthropology," p. 260.

[152] Hatch, Elvin, Culture and Morality: The Relativity of Values in Anthropology, (New York: Columbia University Press, 1983), p. 29.

[153] Hatch, Elvin, Culture and Morality, p. 32.

[154] Of note is the historical context in which the theory of relativism grew, and the triumph of Boasian thought. These intellectual developments came soon after the end of WWI, what has been called the end of American innocence. There is a mention by Hatch of this correlation -- a sense of pessimism in the world linked to growing feelings of relativism; times of optimism produced searches for universal human principles and the unity of the species.

[155] Spiro, Melford, "Cultural Relativism and the Future of Anthropology," p. 265.

[156] See Meiland's "On the Paradox of Cognitive Relativism," Metaphilosophy 11 (2) (1980) for a more thorough discussion.

[157] Swoyer, Chris, "True For," Relativism: Cognitive and Moral, (Notre Dame: Notre Dame Press, 1982), pp. 84-108.

[158] Williams, Bernard, "The Truth in Relativism," Proceedings of The Aristotelian Society 75 (1974-5): 223.

[159] Williams, Elgin "Anthropology for the Common Man," American Anthropologist 49 (1947):84-90.

[160] For further study see Mendus, Susan, Justifying Toleration: Conceptual and Historical Perspectives, (Cambridge: Cambridge University Press, 1988).

[161] Hatch, Elvin, Culture and Morality, p. 68.

[162] Hatch, Elvin, Culture and Morality, p. 134.

[163] Hatch, Elvin, Culture and Morality, pp. 137.

[164] Shweder, Richard A., "Ethical Relativism: Is There a Defensible Version?" Ethos pp. 210.

[165] Shweder, Richard A., "Ethical Relativism," p. 212.

[166] Shweder, Richard A., "Ethical Relativism," p. 212.

[167] Gould-Martin, Katherine, and Ngin, Chorswang, "Chinese Americans," Ethnicity and Medical Care, ed. Alan Harwood, (Cambridge, MA: Harvard University Press, 1981), pp. 155-157.

CHAPTER 6: Application and Resolution

Having looked at both the Western and Chinese conceptions of the individual, the family, and medical care, and the notions of relativism and tolerance, I now consider the test case from the perspective of each cultural system. The Western model, with its emphasis on the primary role of the individual in society, seems to require a certain equity among individuals and the guarantee of certain "rights," among them the right to decide for oneself what is best. The Chinese approach demonstrates a subversion of the individual and a notion of interconnectedness which potentially more accurately reflects the cultural composition of each "person," yet allows the possibility for individual rights to be forgotten.

Western Approach: Principles and Rights

One approach a Western-oriented health care team might take (in accordance with legal doctrine and individual responsibility) would be to tell Mrs. Lee the truth about her illness.[168] This would most likely entail calling in a hospital interpreter and telling the news. After this revelation, there would be a review of the treatments available and/or the remaining options, such as pain management, symptom control, etc. While this approach would respect the values of autonomy and the principles of informed consent, there would be numerous positive and negative repercussions for all involved -- Mrs. Lee, her family, and the providers.

Effects on the Patient

Divulging all information to Mrs. Lee would produce both positive and negative results. On the positive side, she would be given a chance to express her own wishes regarding her care. She may have specific plans regarding her life or lifestyle that would change as a result of the diagnosis. She may have been meaning to write a will, change the existing one, go back to her home country,[169] or tell a loved one some important news she has been keeping. If the time remaining for her to live were longer, she may have trips or other projects she would like to complete before her death. If there were therapies or surgeries that needed her approval or rejection, these decisions could be made.

However, many of the consequences might be negative as well. In light of the described role of the individual in Chinese health care, Mrs. Lee might construe this outright revelation as the physician's loss of hope for her recovery. Furthermore, Mrs. Lee might see her family as not caring for her because they let the physician bring such bad luck upon her. The patient could then lose hope herself and sink into a profound depression. Given the severity of her illness, she could die in this state, depressed from emotional abandonment and isolation. Mrs. Lee, forced into the individualistic model of Western medicine in her last days, would be cut off from the world and those closest to her, her family.

Effects on the Family

The family might feel relieved that the health care team revealed the diagnosis and asked the patient to make all the decisions. The team's intervention may alleviate the burden of trying to control who knows the damaging information. It would also save family members from trying to decide what therapies to pursue, etc.

However, by refusing to obey family members' wishes by telling the patient her diagnosis and requiring her to make decisions, the health care team may have insulted the family's beliefs. Their familial roles as intermediaries between the physician and Mrs. Lee would have been overruled by the Western health care system and its devotion to the doctrine of informed consent. Family members may feel that they have not served their mother well in her time of need, because they have not fulfilled their protective decision-making and caretaking role.[170]

The family also may feel resentment and anger towards the physician and other health care providers for cruel and unusual behavior towards a dying person. This anger will further mount if any of the life-prolonging options they would wish for her, such as CPR and intubation, are not tried.[171] This situation easily escalates into a conflagration between the health care staff and the family members, as family members attempt to "force" the physicians to pursue a particular course of action with threats of litigation.

While this escalation may occur in the Western health care system with "Western" patients, the cross-cultural problems (such as differing customs, interpretation difficulties, etc.) only highlight the feelings of isolation and resentment. This isolation, coupled with a medical system that still disempowers many patients through an incomprehensible medical language, a bureaucratic paperwork behemoth, and an overwhelming sense of individual unimportance (caused by the hurried postures and intonations of the staff, and by lengthy waiting periods in physicians' offices and emergency rooms) can only serve to increase distrust and resentment by family members.

Effects on the Staff

The physician and other members of the health care staff will be affected by the course of events as well. The physician and staff members may have felt they were helping the patient "accept" the terminal diagnosis, yet find themselves treating a clinically depressed patient who feels isolated and who can no longer trust her family. The amount of trust in the physician-patient relationship may also decrease, thus hindering future interactions. In addition, the health care providers may create an adversarial relationship with the family by measures *they perceive* to be benefiting the patient.

Chinese Approach: Family Duty

The Chinese approach asked for by the family in the test case and documented in the literature would likely result in the family making all the decisions. They would decide what (if anything) to reveal to the patient about the diagnosis and would decide what sorts of therapy to pursue. This coincides with the family's role as the locus of responsibility for the patient. While this reflects Chinese cultural standards, this approach poses different benefits and problems.

Effects on the Patient

The Chinese model benefits the patient by allowing her to cope with her illness in any way she wishes. She may deny that it exists if she does not have to answer questions or provide direction to her providers. She can enjoy the support of her family and friends and not be bothered by specific questions about her treatment. She may also be worried about the effect of her impending death on her family. If they do not acknowledge her illness, she does not need to face the potentially difficult conversations about family finances, wills, funeral services, etc. She may feel that she is ill or even dying but it may be easier not to discuss her illness if she has no responsibility in the process. She may also believe that the power of the diagnosis, "cancer," can harm her. Not revealing a diagnosis may help her maintain what hope she has left.

While the patient may feel that her family should be making all of the decisions, the concerns from the patient's point of view revolve around issues of individual "rights." These, of course, are framed by the Western emphasis on rights (and my own Western orientation) but it is important to understand their justification and utility. Most importantly, the right to self-determination is the most troublesome for the Chinese approach. For instance, what if the patient really *wanted* to have an active role in the decision-making process? Would she be able to express her views if she wanted to? Her exclusion from the knowledge of the diagnosis precludes even her choosing *not* to participate in the decision-making process.

Additional problems involve the possibility of the family's neglecting the patient. While this is not specific to a Chinese approach, or any particular approach for that matter, excluding the patient from the process requires a trust of the family which cannot always be assumed. Given the high cost of medical care in the U.S. today (especially compared to other countries), there will most likely be some underlying financial pressure. The family may choose to discontinue therapy for other than altruistic reasons.

Another example, in the same vein, arises out of cultural taboos, social hierarchy, or ostracization. Some members of Chinese families are treated differently because of their status in the family. Low or diminished status puts them at a higher risk for neglect. For instance, an unmarried aunt who lives with her brother's family may not have had adequate breast exams or pap smears because of a failure to acknowledge those parts of her body.[172] The Chinese approach may be directly harmful when cost, family social position, or other factors influence the family's decisions.

Effects on the Family

From the family's perspective, they may be gratified that the Western health care system honors their sense of proper roles and allows them to practice their cultural beliefs. However, this assumes they all share the same beliefs to the same degree. Some members of the family may be more acculturated than those shaping the decisions. In that respect, a unifying family choice or voice may not exist. If such is the case, what should the providers do? Wait for a vote? Is family majority good enough, or should there be consensus?

Effects on the Staff

Staff members may feel that the Chinese model requested by the family helps the patient by allowing her and her family to maintain their cultural beliefs and values. The health care team may feel that different cultural values should be respected at all times, especially in health care delivery.

However, some health care providers in the U.S. may face a very difficult time with the Chinese approach. Trained in the Western model, they refer to autonomy and informed consent to both justify their actions and to help patients make decisions for themselves. Furthermore, providers may have little experience with different decision-making structures; they may view an alternate approach as a deviation from and a threat to the newly accepted doctrine of the role of individualism. Furthermore, the deviation from the Western norm would produce legal problems for the staff as well. It would be difficult for a staff member to legally defend such a structure if litigation ensued.

Difficulties in Resolving Differences

The problem remains in finding areas of congruence between the two systems. Are there universal principles to refer to? Consider those relativists who attempted to define universal goals or a psychic unity. The principle of humaneness could be used as a criteria for the merging of cultural beliefs. The formulation might proceed as follows: Differing cultural values within U.S. society would be acceptable if they reflected the principle that it is wrong to do harm to others and it is right to benefit them. The application to the test case, however, doesn't produce a clear result.

Reference to the same principle of humaneness does not result in the same outcome for both cultural systems. The case in which the family doesn't want to tell the patient her diagnosis and wants to make all the treatment decisions may reflect the family's belief in the duty to care for their loved one, an example of Hatch's moral universal of beneficence: it is wrong to do harm to others. The same universal principle, however, may compel Western medical practitioners to tell the patient her diagnosis, and to ask her to make her own treatment decisions because she could be "harmed" otherwise. Reference to a universal principle does not resolve anything. I suggest, then, that the test case refers to non-universal cultural characteristics and values which do not allow facile cross-cultural resolution. As Shweder states, "any moral decision is the product of a line of reasoning involving principles and concepts, some of which are universally distributed and many of which are not."[173]

Three Conflicting Concepts

There are three differing, and perhaps incommensurable, principles and concepts upon which each system bases its approach to such a situation. Each system interprets these three concepts differently and these concepts fundamentally outline the conflict. These include differences in definition of the person, variation in the ethical unit of discourse, and a focus on kinship roles.

One such concept concerns the notions of personhood. As outlined in Chapter 4, the Western notion of personhood identifies the self and the person by the limits of its biological being. The individual is paramount and the society has been constructed to serve the interests of individuals. Chinese societies tend to stress the concept of personhood as the interconnection between persons; collective interests override individual interests.

Another area of discrepancy lies in the ethical unit of discourse. This refers to Shweder's list of culture-specific features of moral codes. The Western model employs a rights-based approach. The approach uses individual rights as the basis for legislation, policy, and moral discourse. The Chinese culture, however, employs a duty-based approach which resolves ethical conflict by reference of specific cases to the duty of compassion. Physicians must follow the duty without regard to consequences.[174]

The focus on kinship roles in Chinese culture further illustrates culture-specific differences. Kinship roles define how families should make decisions, e.g. for treating the patient or not telling the patient a diagnosis. A patient's specific roles and duties may prohibit her from acting or deciding without consulting other family members. Furthermore, kinship roles may urge the family, out of a sense of duty, to ask for all possible treatments. Western culture contains little on specific or proscribed roles of the family during a competent patient's illness.

These differing concepts of Chinese and Western cultures result in varying interpretations of dilemmas. In the given case scenario, the family members might not see the situation as presenting an inherent moral dilemma for the Western system. Western medicine and values, however, would demand that the patient participate in the decision-making process. Eliminating the patient's role in the Western system, without her explicit consent, is morally suspect.

Resolution

While these two cultural systems are at odds, one solution may come simply from the providers and the family trying to understand the other position. A middle ground should be found; the providers may be able to make some modifications of their doctrine of informed consent, and the family may allow the health providers to openly communicate with the patient.

Bernard Williams alludes to this type of compromise in his piece on the truth in moral relativism. He states that when two sides are in notional, rather than real, confrontation with each other, the opposing sides can illuminate each other's way of life. "Certain features of an alien way of life can stand to us symbolically as emblems of conduct and character to which we have certain attitudes in our own society."[175] By attempting such introspection, each side may see the potential benefits in a modification of their own values.

Modifications of the Chinese Model

The Chinese model might consider the advantages of letting individual patients participate more in the decision-making process. The individuals obviously have an interest in what is happening to them, and disclosure may lead to decreased abuses of patients in disadvantageous positions. Furthermore, given that the case presented occurs within the Western system and that patient choice is the dominant model here, it might be basically impossible to *not* somehow compromise with the Western model. (Again, this brings up the issue of how much should a person change her values when in another cultural system.)

The value of a respect for the principle of patient autonomy is that a patient can choose if she wants to be included in the decision process. If she does not want to be involved, she can designate someone to make decisions for her. If she does want to become involved though, shouldn't she have the ability to do so? It seems the only way to grant this possibility is to have the patient choose for herself.

Modifications of the Western Model

What can the Western model learn from the Chinese model? The interconnection of individuals, their families and communities seems to be the most obvious. Many would argue that the patient's autonomy has assumed too large a role in medical decisions.[176] The Western model relies too much on a purely rational self, distanced from close and trusted others.[177] An increased role of the family in medical decision-making would more accurately portray a connected, interrelated conception of personhood and allow for a more humane and compassionate method of decision-making. The larger role of the family may help in other ways as well.

The Role of the Family

While the patient herself can provide much information about her medical history, significant life experiences, etc., to help the physician-patient interaction produce appropriate therapeutic decisions, the patient's family can play an important role as well. Given the emphasis on individual liberties and responsibility, the role of the family is downplayed in the U.S. Taking into consideration only the individual's input, however, often fails to recognize or preserve interpersonal and social ties.[178] Through including the family in decision-making, two benefits occur: first, cultural norms for the physician, patient and family, are illuminated; second, the family can express its own wishes or desires regarding treatment options, etc.. John Hardwig argues this last point vociferously in his attempt[179] to establish the importance of family input in *any* decision, not just those involving different cultures.

The family can act as a guide to the role of physicians in the patient's own culture. The physician can observe the family dynamics to ascertain what is expected of him/her. If the physician is expected to speak only to certain members of the family about diagnosis, treatment, etc., it may become apparent by one family member always stepping forward to ask for information about the patient, controlling the translation, and deciding which visitors to allow and when.

Families may also help physicians by providing information both about the roles patients usually play/expect. Consider again the test case. The family told the physician not to divulge information to the patient, implying that the patient did not expect to be told of the diagnosis. This potentially indicated the low level of personal responsibility normally taken by the patient. The physician must appreciate this perspective enough to at least study the situation more before assuming the patient has a "Western" orientation. The level of personal responsibility the patient wishes to take can profoundly affect the physician-patient relationship and should be recognized and influence the physician's approach accordingly. If the patient does not want to be involved in the decision process, the physician should not include her.

In addition to making the physician aware of the level of personal responsibility a patient expects, the family can help the physician by providing valuable information about the patient's values, cultural heritage, and experiences. Since the patient may not be fully aware of some of this information as well, the family emerges as an extremely valuable resource. The patient's history, which may appear unremarkable during physician questioning, can come alive with a background contributed by family members. (Indeed, it is commonly taught in medical school that spouses often provide valuable information regarding a patient's history.) When the patient comes from a different cultural system, this added information can be beneficial -- even crucial -- because it provides information about a patient's cultural background in addition to the medical history.

Conclusion

Both the Western and Chinese models inadequately address the problems presented by the case. A compromise position arises from looking at those aspects of each model seen as a benefit to the patient. (I assume that this notion of benefit could only be answered, given my Western framework, by the patient herself.)

The Chinese model could benefit from an added role of the patient and the Western model would benefit from an increased role of the family. Since the case occurs within the Western system, the increased role of the patient is already established. Legal mechanisms in place such as informed consent forms attempt to ensure it. Allowing family involvement is more problematic for the current Western system, and it is to this issue that the next chapters are devoted.

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[168] Beyene, Yewoubdar, "Medical Disclosure and Refugees," West Journal of Medicine 157 (Sept 1992): 328-332.

[169] A wish expressed during a pilot study at San Francisco General.

[170] The term "role" perhaps connotes an air of rigid formality. Rather, consider the actions of the family as reflecting their final tribute and respect for their loved one, helping her through this troubled time.

[171] This situation seems more probable than the one with which more Westerners are familiar in terms of withdrawal of care. I suggest that more Americans are familiar with physicians "doing too much" or taking "heroic measures" when the actions are not deemed necessary by the patient or family. It has been noted that in some cases of Chinese patient/family interactions, demanding the most extensive treatment shows further dedication to the ill relative.

[172] Mo, Bertha, "Modesty, Sexuality, and Breast Health in Chinese American Women," Western Journal of Medicine 157 (Sept. 1992): 260.

[173] Shweder, Richard A., "Ethical Relativism," p. 212.

[174] Qui, Ren-Zong, "Medical Ethics and Chinese Culture," p. 156.

[175] Williams, Bernard, "The Truth in Relativism," Proceedings of The Aristotelian Society 75 (1974-5): 225.

[176] See the works of Callahan, Pellegrino, Hardwig, Blustein, or Nelson.

[177] Parens, Eric, "Keeping Difficulty in Play."

[178] Fabrega, Horacio, Jr., "An Ethnomedical Perspective," p. 612.

[179] Hardwig, John, "What About the Family," Hastings Center Report, March/April 1990.

CHAPTER 7: Models of Family Involvement

In the following chapters, I shall outline three models of family involvement in decision-making -- family autonomy, family conference, and offering autonomy. The first two approaches provide increased involvement of the family in the decision process. However, I find both of these models inadequate because they do not adequately protect the patient from possible abuse or neglect. The final model allows patient choice *within* the context of greater cultural sensitivity. While it relies on certain assumptions, this third model appeals to both the current Western individual orientation and the Chinese conception of the interconnected person. It allows the patient to choose which model of decision-making is best for her. The following summary chart outlines the advantages and disadvantages of each model.

Comparison of Models of Decision-Making

Model	Advantages	Disadvantages
Family Autonomy	Reflects traditional values Family decides Patient role determined by family Culturally appropriate	Assumes values of patient Assumes unified family Potential for patient abuse Violates Western legal and ethical norms
Family Conference	Promotes family involvement Recognizes family interests	Practical application probs. Potential for patient abuse Could overrule patient Artificial setting
Offering Autonomy	Patient has choice of model Can allow family involvement Works within current law Safeguards against abuse Encourages but does not require patient involvement	Assumes open and honest communication possible Assumes no biases of family or provider Assumes accurate non-verbal interpretation

This chapter and the next outline the "family autonomy" and "family conference" models, respectively, and the advantages of and objections to each. Chapter 9 describes the model of "offering autonomy" and raises some questions about Western assumptions in medical decision-making.

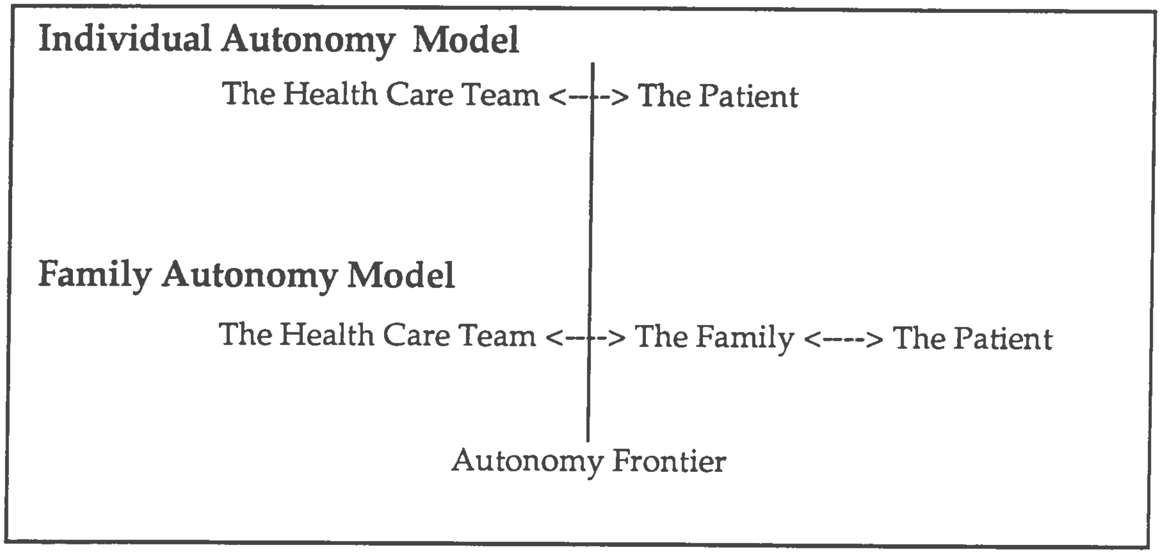
Each of these models, though, approaches conflicts of value from within the current Western system. On another level, the resolution of cross-cultural conflicts would have to address larger issues. These would include the extent to which the health care system in the U.S. must change to provide better health care to citizens and the role of ethnic communities in shaping the health care delivery and health care policies. Chapter 10 proposes some solutions both in the clinical setting and in the larger social context.

Family Autonomy

The "family autonomy" approach respects the Chinese conception of self and retains some aspects of Western autonomy. This model redefines the Western view of autonomy to include the autonomy of the family. It allows increased interaction and inclusion of the family, taking into consideration the Chinese conception of the "person." The model fails, however, to guard against potential abuses or neglect of the patient.

Consider autonomy as defined from a familial stance. If autonomy values persons making decisions for themselves and a Chinese conception of person goes beyond their physical bodies and encompasses their family, can the Western value of autonomy allow their family -- their conception of the person -- to make decisions for their ill relative? If we consider the evolution of the term "autonomy" from the ancient Greek city/state meaning, literally, *political self-rule* to the self-governance of the individual person, might a legitimate conception of the respect for autonomy consider the in-between state, the family, as an autonomous unit? If so, a respect for autonomy would be upheld by the relationship involving the family and the physician.

This linear approach allows the health care team to interact only with the patient's family regarding treatment decisions, diagnosis revelations, etc. The term "linear" indicates the interactions between participants as shown below:



While the Western view of autonomy designates the border between the health care team and the patient as the limits of personhood, the Chinese "person" might experience the second model as the appropriate boundary.

In this model, the family assumes the active role in the therapeutic relationship. The family discusses the patient's condition, therapeutic measures, and options with the physician, acting as liaison with the medical staff. Hence, the patient's family, instead of the patient, works as an autonomous unit. While this type of interaction dominates in many societies,[180] Western medicine would find this form very disturbing.

Allowing the family to play this role in the therapeutic relationship, although perhaps "culturally sensitive," is not without perils. It may be that this type of decision-making model provides good patient care. However, the benefits for some patients with this system may be countermanded by the potential for patient abuse. This model of decision-making would contradict the values present in society enough to disallow this model in the current medical and legal system.

Benefits/Drawbacks for the Patient

The benefits to the patient constitute the most impressive arguments for this model. When the family works as an autonomous unit, the patient is treated in the way most culturally appropriate for her. Furthermore, the family is also equipped with additional information about the patient's life experiences and desires in order to adequately inform the physician when consulting about therapeutic options. Allowing the family to provide such information helps to avoid any difficulties the patient has in voicing fears, frustrations, or desires regarding her care. This allows the patient not to disclose personally painful or embarrassing (yet perhaps pertinent or even crucial) information, while helping to improve the medical care.

The family controls the information and can tell a patient all of the information or none of it, depending on what the family deems appropriate. This is both an extremely important yet problematic point in culturally appropriate medicine. Many societies believe (as U.S. society believed in the recent past[181]) that revealing important information regarding the patient's diagnosis can be detrimental to the patient's condition. The full disclosure of a diagnosis may be seen as an omen, or portent of the event happening.[182] As explained earlier, the mere mention of a cancer diagnosis can cause a patient to lose hope. This situation could be avoided by treating the family as an autonomous unit itself.

Benefits/Drawbacks for the Family

In addition to benefiting the patient, the structure in which the family works as an autonomous unit benefits the family as well. Through it, the family attains a sense of involvement often missing in Western medicine. Each decision arises out of genuine familial interaction and decision-making. This system respects the dynamics of a particular familial system. In addition, the system would also respect the cultural beliefs and practices of the patient and family. (Considerations of family will, however, vary with one's definition. Whether partners, significant others, friends, or only legally related relatives fall under the definition of "family" is beyond the scope of this project.)

Negative effects to the family under this system would be minimal. Decisions being made under this system might bring up differences and clashes between family members, thereby decreasing family unity. This conflict might be exacerbated by family members' varying levels of cultural integration. For instance, when making decisions about a grandparent, the children may be more influenced by traditional cultural norms than the grandchildren. If such is the case, the grandchildren's opinions may differ from those of their parents about what information to reveal to the patient, what to offer in treatment, or how much to ask the patient her wishes. While the resulting family tension might produce long-standing conflicts or inter-generational feuds, such conflicts could arise in any decision structure.

Benefits/Drawbacks for the Staff

The benefits for the staff in this model involve the professional and personal satisfaction produced by delivering culturally "appropriate" care. Under this system, staff members would be following a standard of care which the patient expects. This standard of care, though perhaps foreign to the staff, may benefit the patient greatly.

While the staff may benefit from providing culturally appropriate care, the structure would admittedly violate the Western norms of informed consent and patient autonomy. If these concepts guide other aspects of the physician's and staff members' professional lives, how could their violation not cause apprehension and discomfort? If the patient is not told of the diagnosis because of the family's intervention, the physician may find herself caught between respect for cultural differences and (in the Western legal view) negligence in obtaining informed consent from the patient. The family would be informed of the options, just as the patient in Western medicine would be. The family would give their consent in the same way the individual gives his/her consent in Western society. But in the cases in which abuse could occur (for instance, if the family could benefit from the patient's death, or if the family would not acknowledge the need for medical attention) the physician might not be willing to act according to family autonomy standards. If litigation occurred, the health care team would be very vulnerable. I suggest that the current legal climate in health care virtually eliminates this model as a workable option.

While this entire system seems to grossly devalue the patient's autonomy, this type of interaction may be appropriate. The lack of autonomy afforded the individual under this type of structure may be perceived as damaging because we approach the situation using Western beliefs about what is good medical care. A conception of family autonomy, though, might provide a compromise position between the Western value of autonomy and the Chinese value of interconnection.

Concerns About Implementation

Some might be willing to accept the Chinese models for familial autonomy, withholding truth, etc.,[183] but what about the concerns outlined above in the application of the Chinese model? Are there some cases in which allowing the family to function autonomously may be detrimental?

Jeffrey Blustein lists the faults of this model in his criticism of the "communitarian" approach to family decision-making. In this account, the patient "is too enmeshed in a network of relations to others to be properly singled out as the one to make treatment decisions."[184] For communitarians, the patient may belong to a close-knit and harmonious family whose values as a community are distinguished from those of the providers. Here Blustein describes communitarians as not necessarily being from a different culture; even though this paper emphasizes cross-cultural interactions, the issues raised about individual vs. group-based identity are very similar.

In the communitarian model, members of a community recognize their common ends and identity, and would act accordingly when a family member needs treatment decisions, etc.

> In these cases, the patient would not need to be protected from family pressures for inappropriate treatment. Rather, the family would act as an advocate for the patient vis-a-vis the physician, and the family decision-making would put patients on a much more equal footing with caregivers.[185]

In this setting, the family is a community of love; questions of fairness and individual rights are not needed because of a spirit of generosity among the community members.

Blustein's arguments against the communitarian approach vary in scope. First, he states that even if communities (or families) were ideal, the mere existence of a community does not require or guarantee that members espouse identical views on all matters of value or the good. There may exist varying ideas about how to rank different components of a shared conception of the good, or on how to go about achieving that good, or about what risks are worth the effort. Even if they agree on a common conception of the good, the notion that all members of a community will agree on a specific medical treatment seems too idealistic. Disagreements, even within communities, are expected. Because of this natural tendency,

> Individual rights have an important place in community because the existence of community does not eradicate serious disagreement about ends, about the relationship between particular choices and shared ends, and so forth.[186]

Rights are important even in ideal communities because individuals remain "numerically distinct" and both retain their own distinct perspectives and an interest in expressing those perspectives.

In cases in which the family does not represent a unified community, but one fraught with dissension and conflicting interests, an even stronger argument exists for the maintenance of patient autonomy. In such situations, questions of justice for the patient rise to the fore and the absolute value of patient autonomy seems clear. Rights protect the interests of the patient when the family can't be trusted to have the well-being of the patient at heart and also, as above, when family members who generally share a common set of values with the patient do not agree with the wisdom of the patient or her particular conception of this situation. Rights protect the agency of the individual.

Conclusion

This family autonomy approach, then, cannot be blindly and unilaterally applied. The dangers which result from agency indiscriminately given to the family include not heeding the patient's desire for or against a particular treatment, or, perhaps more demonstratively, what most people would term "abuse" or "neglect." This might occur, for example, when an unmarried woman was suffering from breast cancer and the family wouldn't acknowledge the illness and therefore would not advocate aggressive treatment. In addition, a wealthy patient might provide an opportunity for the family to benefit from the death of their relative.

But has the Western version of autonomy been modified in any way? Are we merely deferring to the Western view and refusing to accommodate the Chinese conception of personhood? Two other approaches may produce a middle ground which respects individual autonomy but allows the patient to decide which model to follow. The next chapter suggests a "family conference" approach whereby members of the family meet and openly discuss their wishes. A third model, entitled "offering autonomy" and explained in Chapter 9, provides an even more workable compromise that allows patients to decide, directly or indirectly, how they want decisions made.

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[180] Surbone, Antonella, "Truth Telling to the Patient," JAMA 268 (13) (1992): 1661-2.

[181] Oken, D, "What to Tell Cancer Patients."

[182] Long, Susan O. and Long, Bruce D., "Curable Cancers and Fatal Ulcers: Attitudes Towards Cancer in Japan," Social Science and Medicine 16 (1982): 2101-2108.

[183] Pellegrino, ED, "Is Truth Telling to the Patient a Cultural Artifact?" JAMA 268 (13) (1992): 1734-1735.

[184] Blustein, Jeffrey, "The Family in Medical Decisionmaking," Hastings Center Report, May-June 1993, p. 8.

[185] Blustein, Jeffrey, "The Family in Medical Decisionmaking," p. 9.

[186] Blustein, Jeffrey, "The Family in Medical Decisionmaking," p. 10.

CHAPTER 8: The Family Conference Model

Another approach takes a less radical stance on how patients and families should make decisions. Instead of vesting all authority in the family and opening the possibility for abuse or neglect, this approach allows families to express their interests in the medical sphere, along with the patient. This may allow families to express their interconnectedness in a way that would respect their conception of their -- and the patient's -- view of "personhood." The drawbacks in this approach, however, concern the difficulty in implementing this approach, and the potential difficulty in discussing this approach with a patient not willing to discuss this option.

The family conference approach acknowledges the family unit as having its own interests and desires. These interests may conflict with the patient's in deciding treatment options, standard of care, etc. John Hardwig states that the "interests of the family are dramatically affected by decisions about the patient's treatment... [and] the family members may a have a *greater* interest than the patient"[187] (emphasis added) regarding treatment options. Consider the case of a family member with a kidney stone. A new procedure costs $20,000 and is not covered by the family's insurance. The family's insurance does cover the traditional procedure which involves general anesthesia and a great deal less cost. The money, which may even be available to the family, represents years of hard work and sacrifice and has been designated as the down payment on a new house in a neighborhood with excellent schools.[188] The family has a keen interest in the treatment options as they, too, will be profoundly affected by the decision. If the family members' overall interests include education of their children, wouldn't they have a very real and pressing interest in the treatment options? Is it possible to discuss the lives and choices of patients as distinct from the lives of those who are close to them?

The current structure of medical care in this country and the legal and public policy that surrounds informed consent have, however, formulated an isolated and distinct medical decision-maker. Hardwig states that "by implicitly suggesting that patients make "their own" treatment decisions on a self-regarding basis and supporting those who do so, such an ethics encourages each of us to see our lives as simply our own."[189]

Hardwig suggests that two mechanisms have led us to forget the interconnection among family members. First, he points to the historical fact that illnesses in the not-so-distant past were typically of shorter duration and led either to recovery or death. Either event rarely had financial impact of the magnitude that "one's future [was] mortgaged to the costs of the care of family members."[190] Second, the biophysical model of disease has led many to believe that illness and treatment occur within a single body and that they, therefore, do not affect others. In any event, the resultant structuring and valuing of patient preferences does little to acknowledge other interests.

A solution would consider the non-medical interests of the family (and patient) as well as the medical interests of the patient. This is based on the presumption of equality and fairness of all interests.

> The interests of patients and family members are morally to be weighted equally; medical and non-medical interests of the same magnitude deserve equal consideration in making treatment decisions.[191]

While Hardwig recognizes the probability that this equality model could be defeated on the basis of special consideration of a particular family member's special interest, the "burden of proof" lies with those who would advocate special consideration, including the patient herself or her advocate.

Freedom from pain and the preservation of life itself both demand special weighting within such a system. These, as generalized goals of the medical model, may be strong enough to outweigh the family's interests most of the time. However, the process still recognizes the other family members' interests. This recognition also holds that such interests may occasionally override the interests of the patient.

Practical Problems with the Model

The practical side of this model proves quite difficult. Who should play the role of "judge"? If both the patient and her family have interests in the patient's treatment, how should such interests be represented? Does each family member get one vote? Does the patient get one vote, the family get one vote, and the physician or perhaps a disinterested party get one vote in the case of a stalemate? While this sort of reasoning could proceed ad absurdum, it is important to understand the goals of the process.

While Hardwig outlines important issues about patient advocacy and the physician's role in presenting the benefits and disadvantages of any treatment, he does little to present a concrete system for dealing with inter-family conflicts, or family/patient disagreements. While it lacks a specific implementation system, I believe the approach is important, as it allows all involved to consider more than just the patient's interests. To forget that the patient has personal and social ties as well as obligations and responsibilities seems to oversimplify the entire process and exclude those closest to the patient. The crucial asset of the system is that it recognizes that others have interests in the choices and the process. The actions of one person usually affect far more than just the individual.

With this recognition comes the requirement, Hardwig states, of family involvement in the process, "with all competent family members whose lives will be affected participating."[192] Family conferences would be morally required whenever there is a major change in the prognosis, treatment goals, or options considered. Whether the conference reveals deep affection and concern or antagonism and bitterness, the recognition of the interests of family members -- even if opposing -- would create an environment of communication whereby such recognition and discussion could lead through mediation to a fair decision for all.[193]

Theoretical Problems with the Model

Consideration of patient interests as one of a number of important interests is not terribly revolutionary, given the previous discussion of the Chinese conception of the person. I would argue that the larger focus of responsibility and interconnection between family members requires the Chinese patient to acknowledge these issues without the need for a "decision-making model." The patient would recognize that decisions about her health care also involve certain responsibilities towards her family.

If, however, the purpose of discussing any plans with the patient is that she has the ultimate decision in what is done with her body, leaving this decision to anyone else diminishes her role as a moral agent. While reminding patients that they should consider other interests as well as their own might facilitate a more accurate perception of their larger responsibilities, *requiring* that families be involved in the decision seems extreme. This system does little to protect the patient against abuse or coercion. The family, if united in their votes, could possibly overrule the patient's wishes. The system, while facilitating discussion, may still overrule the expressed views and wishes of the competent patient. This objection is similar to the one against the Chinese system in which certain family members, because of their diseases, status, or any number of factors, might be categorically denied care that both they and their physicians would deem valuable and useful to them.

When the family is under severe financial strain and chooses to discontinue treatment in an effort to lessen the burden, or when the patient with the illness is in a less advantageous position within the family system, the family would not necessarily choose according to the patient's desires. Such circumstances require a more active role from the individual patient because of the harm possible. Perhaps the process is different in that the patient would be openly able to express her wishes in a conference setting. I suggest, though, that the outcome might not change and the potential harm done to the patients would be too large to advocate the implementation of this model.

The harm done to the patient in allowing her wishes to be overridden would negate any advantages gained by the realization of the other, possible competing, interests of her family. Secondly, by diminishing the role of moral agency, this scheme would perhaps have far-reaching implications for other spheres of life. For example, would parental consent be needed for a 24-year-old atheist woman to have a blood transfusion? Would a unified vote from her Christian Scientist family prevent her from obtaining such a transfusion? These ramifications are clearly too great for the unqualified acceptance of this system.

Consent

Consent of the patient holds the process in check. It is only through this consent that such a decision-making model can proceed. The patient must have the option of deciding against holding a family conference. While this departs radically from Hardwig's requirement that these family conferences be mandatory, it seems that consent is the only mechanism available that would guard against the abuses of the patient mentioned above.

Through consent, the patient could agree to such a decision-making system. The patient would be given the opportunity to employ the conference as an important tool to making decisions regarding her future care. (It may be that these conferences would be suggested in certain situations, much like they way ethics committee consultations are provided only on a request basis.) However, if the patient chooses to not convene a family conference, this must be regarded as a valid wish to make these treatment decisions on her own criteria.

However, this consent process must consider the vulnerable position of the patient, the power of suggestion, and the disenfranchisement of the patient in the physician-patient relationship. The consent process for such a family conference should be structured to minimize the effect of physician advisement or suggestion of such a conference, and thus might best be begun by a social worker, religious representative, or patient ombudsman.

Benefits of Family Conference with Consent

A consent process which regularly allowed, or even suggested, family conferences would have many of the advantages of the interconnected system and yet would retain some mechanisms to guard against abuse or neglect. If the patient felt a need to consider the family interests (e.g. had the desire to reflect the Chinese, or other non-Western, view of personhood, or merely wanted to have the family's input on such an important issue), she could agree to such a conference and an explicit discussion of the goals and options for treatment.

If the patient did not want such an explicit framework or conference for discussion of these issues, this model would not function. She could refuse a "conference" but still solicit information and opinions from family members. This would be less structured in format but perhaps more in keeping with the experiences she has had in these types of family discussions. A formal atmosphere may not be as useful for the patient as informal discussions among select, trusted family members and friends.

Finally, if the patient felt that the conference wouldn't help her, would cause her to become more confused about what she wants, and/or prod her into refusing or accepting a treatment by virtue of others' influence, she should be able to refuse such a process. This would help to protect her from possible abuse or neglect situations. She would refuse the conference and make all the decisions regarding her care, independent of the influence of the family conference model. She could, again, choose select people to confide in, ask questions of, etc. but these would not be confined to or exclusive of her family.

In each of these instances, the family functions not as an autonomous unit, but rather as another participant in the decision; the family would not be the sole possessor of decision-making power.

Cultural Problems of Family Conference with Consent

The main argument against this solution stems from the cultural role of the patient in this process. Why not just ask the patient if she wants to be included in any decisions surrounding her care, including whether she is to be told the diagnosis at all? I would suggest that this argument is problematic on a number of levels. First, the model of open communication and discussion is very specific to Western biomedicine.[194] Patients may not be accustomed to such questions and not know how to respond. If the patient still bases her expectations in a non-Western cultural system, such discussions might seem not only foreign, ignorant, and rude, but may not be understood at all. "Why is the doctor asking me these questions?" "How am I supposed to respond?" The dialogue to discuss the possibility of family conference or other family issues may not proceed as the social worker or physician envisions.

Second, the level of responsibility taken for a diagnosis, in Chinese culture, changes with the level of severity of illness. Since the amount a patient is shielded from the decision-making process depends on the severity of the illness, the fact that a physician is even asking the question could imply the worst situation. The question could be understood as, "So would you want us to tell you that you have cancer, or not?" By merely asking the question, the purpose of asking it has been defeated. While the counter-argument would say that these discussions would occur in a long-standing physician-patient relationship, well in advance of the severe complications, the scenario of a county hospital and a high immigrant population would not guarantee such a long-term relationship.

The direct approach to involvement in treatment decisions and diagnosis revelation seems linked to the Western bias of open communication and patient autonomy. Perhaps a better way to approach the situation is through a more subtle, yet still individualistic, approach. This approach is called "offering autonomy" and allows patients to retain their cultural standards while allowing them the option of full information disclosure.

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[187] Hardwig, John, "What About the Family," p. 5.

[188] This case is based on a case outlined by James Lindemann Nelson in his paper, "Taking Families Seriously," Hastings Center Report, July-August 1992, p. 9.

[189] Hardwig, John, "What About the Family," p. 7.

[190] Hardwig, John, "What About the Family," p. 6.

[191] Hardwig, John, "What About the Family," p. 7.

[192] Hardwig, John, "What About the Family," p. 9.

[193] Hardwig, John, "What About the Family," p. 10.

[194] Gordon, Deborah. R., "Tenacious Assumptions in Western Medicine," Biomedicine Examined, eds. Lock, Margaret and Gordon, Deborah, (Dordrecht: Kluwer Academic Publishers, 1988), pp. 19-56.

CHAPTER 9: Offering Autonomy to the Patient

Considering the complications involved in openly discussing the diagnosis and treatment options with patients from different cultures, any approach will have to address the value of patient involvement in the decision process, yet allow patients to retain their cultural norms and values if they desire. One theoretical approach which retains both patient choice and respect for cultural concepts of personhood requires that patients be offered multiple opportunities for discussing their situation, yet does not mandate telling the diagnosis or requiring active participation if the patient does not wish it. Benjamin Freedman advocates this position, which he entitles "Offering Truth."[195] This process has many stages -- listening to the patient and family, discussing with the family why the Western model holds that patients should be informed, negotiation, and offering truth (or autonomy) to the uninformed patient. Through this process, the health care team, the family, and (possibly) the patient will have a much better understanding about which model for decision-making provides the best care for the patient. This may involve relying on the family to make all the decisions, having the patient make all the decisions, or any combination in between the extremes.

Let us apply this model to a situation in which a patient is uninformed of a diagnosis or prognosis for any number of reasons. It may be that during surgery, the severity of the tumor is relayed to the family members, who exhort the physicians not to tell the patient. Another case could be a long-standing disease in which the patient's family brings the patient to the emergency room during an exacerbation of symptoms. The patient is incoherent and the physician informs the family members, as required by law. At this time, the family may ask the physicians to treat the patient, but not to tell the truth. This process can occur regardless of cultural background of the patient and family, but when they represent cultures other than that of the physicians or the legal establishment, the conflict can be heightened.

Listening to the Situation

The health care team should first listen to the family. Only by actively listening can the staff gain an appreciation of both the family's explanatory models of the illness and their thoughts about how the illness is affecting them and the patient. This must be done in an open and nonjudgmental way so that the family can feel comfortable expressing their beliefs and desires, especially if they do not reflect the Western orientation. After listening to the family's situation -- explanatory model of illness, expectations of the Western system, fears of patient involvement -- the staff will have both clearer expectations of what would best serve the needs of the family and will have established a meaningful relationship with the family.

This open and honest listening can give providers the opportunity to establish a trusting relationship with the family. Since this relationship would then be the basis for the rest of the interactions, it is imperative that the family feel their opinions and beliefs are valid and acknowledged. From the relationship grows a willingness to discuss the reasons why the family and patient came to the Western medical system and their expectations of it. The providers can use this relationship as a basis for explaining the Western model of health care and the usual role patients take in it.

Explaining the Western Value of Informed Patients

The next stage of this model of decision-making requires explaining to families the Western value of informing patients. The main arguments for this type of information derive from the potential harm (from the Western perspective) to the patient if she doesn't know about her illness. The first of these arguments outlines the difficulty the staff has in changing their habits of informing patients. If the staff believes the patient has a right to know the diagnosis, not informing the patient -- or even giving her the chance to not be informed -- would go against their own principles, the principles of the institution, and the laws of the country. Any consent the patient gives for treatment without knowing the reason for the treatment contradicts the legal doctrine of informed consent.

Families may not believe that the contradiction of personal principles of the staff or possible illegality has strong claims against them and their cultural norms. As such, the argument about violating standards of care would not deter them from attempting to shield their loved one from the diagnosis, or from the burdens of treatment decisions.

Another Western argument for involving the patient in the decision concerns the potential direct negative impact for the patient if she is left uninformed. The patient may already suspect the diagnosis and her impending death, but feel unable to discuss it with her family or physician because they "had not given her 'permission' to broach the topic."[196] The family's and physician's silence may further alienate her from her connections.

In addition, the health care team can emphasize that once patients know their diagnoses, they often have "unfinished business" they need to complete. This may include finalizing wills, calling loved ones in distant places, settling long-standing family conflicts, or even returning to their homeland.[197]

The third Western argument, and perhaps most convincing for the family, is that the patient's care itself could be compromised by a lack of information. This might include not giving the patient morphine because it would alert her to the nature and severity of her condition. Alternatively, this secrecy might prevent the use of certain forms of chemotherapy because the common side effects would certainly demonstrate the diagnosis. For instance, the common side effects of chemotherapy -- hair loss, nausea, relentless vomiting -- are clear markers of very severe illness. In each case, the lack of involvement of the patient directly harms her. By trying to help her by withholding information, the family could actually be causing distress or harm.

After explaining these arguments, the family would hopefully understand the Western perspective of offering the patient the chance to become involved. They may not agree with it, but they will have a better comprehension of the Western value of autonomy.

Negotiation

The next stage involves negotiation of a course of action. For the Western system, the most important thing is for the patient to choose which decision making model to follow. Often, the family refers to their cultural heritage and to what they believe patient would or wouldn't want to do. The negotiation, then, revolves around a compromise position where the patient would be offered the chance to express her desires but if the patient did not want to become involved, she would not be forced to. As such, the process would allow her to maintain her cultural identity and norms. If the patient does, however, want to be involved, the Western model would try to allow her this option. The process for this offering of information must clarify what level of information the patient desires, and yet allow the patient not to acknowledge her disease or prognosis, if she does not wish to.

Offering the Option of Truth

Freedman discusses the process of acquiring information as a continuous spectrum. The interaction acquires different characteristics depending on individual circumstances. Patients and physicians communicate through a number of different means; verbal information, non-verbal cues, and body language all affect the interaction. In addition, patient denial can affect how each piece of information is interpreted. A physician may feel convinced she has told a patient the terminal cancer diagnosis, and yet later questioning of the patient may reveal the patient's ignorance of the truth. Full information and absolute ignorance are both relatively unattainable.

Offering autonomy occurs within this spectrum of information-gathering. Rather than determining a patient's lucidity and then proceeding to explain the diagnosis, prognosis, and all possible treatment options, the process of offering autonomy requires that repeated attempts be made to ascertain from the patient how much she wants to know, and how involved she wants to be in the process. Freedman outlines this approach as a compromise between the possible harm associated with patient ignorance and the possible harm caused by callously presented or unwanted information.[198]

The interaction would proceed along the following lines. The patient could be told that she was ill and asked if she had any questions regarding her illness. Does she want to talk? Some people want to know a great deal about their illness -- its name, prognosis, treatment, famous people with the disease -- and some others don't wish to know so much; others want to leave all the decisions in the hands of their physicians or family members. What would she like? What type of patient is she? While this discussion would best occur in the initial stages of the physician-patient relationship, perhaps when the patient is not extremely ill, the current health care system may not allow for this sort of long-term physician-patient relationship. Often the lack of access to health care until a medical emergency precludes establishing a long term relationship.

The answer to this open ended question may be an explicit "tell me everything/nothing" or may be answered by the patient responding with non-verbal cues such as closing her eyes and feigning fatigue or sleep. The importance of the process is that repeated attempts to offer information are made throughout the process.

If no information is desired, the closing remarks should indicate that the health care team will respect her desires, but that if she should change her mind for any reason, the discussion of information could resume at any time.

> The approach relies on one simple tactic: a patient will be offered the opportunity to learn the truth, at whatever detail the patient desires... The important thing is to begin to generate a dynamic within which the patient is speaking and the physician is responding.... Only then can the pace of the conversation and the level of information be controlled by the patient.[199]

If the family maintains that such a discussion will conflict with their cultural norms, Freedman believes the discussion should still occur. It is here when the strength of patient autonomy comes to the fore; the family could be mistaking what its own norms require in such circumstances. They may not consider it a question of cultural norms, but an opportunity to forego a potentially difficult and unpleasant discussion.[200] Alternatively, even if the family's judgment is correct in its interpretation of cultural requirements, the health care team cannot assume that the patient automatically chooses those cultural norms. Depending on her level of acculturation, the number of generations the family has been in this country, and a host of other factors, the extent to which a patient wishes to abide by those cultural guidelines may vary drastically. In addition, cultural values themselves may also change over time, further confusing the notion of "cultural norms."

Offering Autonomy Allows Different Models

The choices of the patient in this framework of offering autonomy could reflect any number of different options. The patient could choose for the family to make all the decisions regarding her care. This choice would closely reflect the model of decision-making of traditional Chinese medical systems and that outlined in Chapter 7. Alternatively, the patient could believe in the value of both family and self-involvement in the process and choose to include the family in all discussions. Similar to the family conference model advocated by John Hardwig, this choice would allow family members to express their interests about all treatments. Finally, the patient could choose to exclude the family entirely. This option, though contrary to Hardwig's opinion, would help guard against the possibility of neglect or abuse.

Regardless of the patient's choice, this model retains the patient's autonomy, including the autonomy of not wanting to know. Choosing to not participate is still an exercise of autonomy. "A patient's right to information is respected no less when the patient chooses to be relatively uninformed as when full information is demanded."[201] Legal precedent confirms this assertion as well. In the case of Cobbs vs. Grant (Cal 1972), the court ruled that "a medical doctor need not make disclosure of risks when the patient requests that he be not so informed."[202]

Objections to this Model

The validity of this model rests on certain assumptions. First, this model assumes that these sorts of discussions can occur without the personal biases of physicians and families influencing the interaction before the patient expresses her wishes. The discussions preceding "offering autonomy," the physical setting, and the way decision-making options are phrased may greatly affect how the patient chooses.

Second, the model assumes a high degree of direct and open communication between the physician and patient. Even for those patients with a completely Western orientation, such communication might not occur because of the vulnerable position of the patient and the status differentials between physicians, families, and ill patients. Indeed, the immigrant status of patients, the difficulty in translating options not usually present within the cultural system, and the common difficulty of locating qualified translators may *further* distance the patient from informed autonomous decisions.

Third, when the patient does not want to discuss these issues, the model assumes the physicians, other members of the health care team, the family, and the translator interpret those "other forms of communication" correctly. Can all those involved, including the translators, interpret body language and other non-verbal cues in the same way? Would there later be a health care team vote on what "the patient looked to the left" means? This example, though exaggerated, illustrates that the reliance on non-verbal cues is at best non-guaranteed, and at worst may produce a totally inaccurate reading of the patient's wishes.

Fourth, the model reveals its Western bias in that the first decision is made by the patient and not by the family.

Fifth, within the strongly legalistic atmosphere of health care delivery, these types of discussions and conclusions would be difficult to document and defend in court. This would hinder the clinical acceptance of such a system.

Sixth, this theoretical approach has *not* been thoroughly testing in clinical settings and its applicability and acceptance are not documented. The offering autonomy model I present here is an adaptation of Freedman's offering truth model and Berlin and Fowkes' model of cross-cultural health care delivery.[203]

Conclusion

Even considering these objections, this model, out of the three examined, offers the best compromise of both working within a given cultural and legal system and allowing for cultural values to be respected. Admittedly, the *patient*, not the family, would choose which cultural models to follow. She would decide what option best serves her needs. From a Western perspective, the "offering autonomy" method minimizes the harm produced. In addition, the method does not contradict any legal precedent or established societal value. It merely interprets patient autonomy to mean the possibility of patients refusing that individual autonomy. The model still upholds the principle of respect for autonomy, but in a form which allows different models of medical decision-making.

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[195] Freedman, Benjamin, "Offering Truth," Archives of Internal Medicine 153 (March 8, 1993): 572-576.

[196] Freedman, Benjamin, "Offering Truth," p. 574.

[197] This was mentioned in the pilot study at San Francisco General.

[198] Freedman, Benjamin, "Offering Truth," p. 574.

[199] Freedman, Benjamin, "Offering Truth," p. 574-5.

[200] Brotzman, Gregory L. and Butler, Dennis J., "Cross-Cultural Issues in the Disclosure of a Terminal Diagnosis," The Journal of Family Practice 32 (4) (1991): 426-427.

[201] Freedman, Benjamin, "The Validity of Ignorant Consent," IRB review of Human Subject Research 4 (2) (1982): 1-5.

[202] Cobbs v. Grant (1972) 104 Cal.Rptr. 505.

[203] Berlin, Elois Ann, and Fowkes, William C., "A Teaching Framework for Cross-cultural Health Care," Western Journal of Medicine 139 (1983 Dec).

CHAPTER 10: Recommendations and Future Directions

Cross-cultural health care delivery presents many difficulties for the American health care system. These difficulties often concern conflicts of value between patients with one set of cultural beliefs and providers with a different cultural framework. One such conflict involves the role of the family in medical decision-making. The example outlined in the first chapter was that of a Chinese woman with metastatic breast cancer whose family requested both that she not be told her diagnosis and that all treatment decisions be decided by the family, not the patient.

After considering Western and Chinese medical ethics and the conception of the "person" in each setting, it became clear that the cultural conceptions and expectations about disclosure, informed consent, and treatment can vary tremendously. Each approach has advantages and disadvantages. The Chinese system may more accurately reflect the true composition of the "person," with interconnections and relationships, but the traditional role of the patient in health care may allow for patient abuse or neglect in some cases. The Western system may provide more safeguards against such abuse but relies on a "desiccated" view of the self as both purely rational and distanced from all connections.

Possible solutions to increase cross-cultural sensitivity occur on different levels: clinical and societal. Clinically, there are some ways for providers to work within the current medical and legal systems to facilitate better patient care and minimize conflict. On a societal level, providers and community leaders can advocate change to the medical system that would allow for greater cultural sensitivity and respect.

Clinical Solutions

The solution for the conflict of cultural beliefs that occurs when the family wishes to make all treatment decisions and conceal a diagnosis from a patient may come from the providers and the family trying to understand the opposing perspective. While each side might not agree with the opposing position, an understanding of both sides will provide an opportunity to reflect on the area of conflict. This would permit each side to perhaps modify its established opinions. From this perspective, the providers may be able to make some modifications of their doctrine of informed consent, and the family may allow the health providers to openly communicate with the patient. The "offering autonomy" model of decision-making allows increased recognition of differing cultural values in the clinical setting, but attempts to guard against abuse or neglect. It allows patients to choose when they want to participate in the decision-making process, but accepts patients choosing not to participate and letting their families make decisions. This model, while not without its weakness, presents the most workable compromise. While it doesn't *force* the Western model of patient autonomy and informed consent, it remains grounded within the current social and legal system. It allows both possibilities.

Recommendations:

Recommendations for the inclusion of cultural and family considerations in clinical decision-making would lead to better health care team/ patient/ family interactions and better patient care. This would require both a re-interpretation of clinical requirements of certain principles and a proactive stance of looking for potential conflicts of value.

1) The health care team should realize that the principle of respect for the principle of autonomy does not necessarily imply that patients at all times

desire to know everything about their illnesses.

The specific details about an illness may not be important to every patient. Any patient might not wish to know the diagnosis, prognosis, treatment options, all risks associated with each treatment, experimental and unproved therapies, treatments in different countries, the amount of research money spent on this disease, etc.

2) Members of the health care team should realize that cultural perspectives may have profound influences on how patients make decisions, conceptualize options, or conduct themselves in the medical setting.

Given the theme of this paper, this recommendation seems somewhat self-evident. Culture and cultural expectations may or may not be extremely important in individual cases.

3) The health care team should understand that the reasons for a patient not wanting to know information are not limited to cultural norms or requirements.

Patients from any culture may not feel comfortable discussing the most graphic descriptions of their disease or the most grim prognosis.

4) Clinicians must realize that clear, unambiguous discussion about the level of information desired will afford patients the opportunity to make these important decisions if they wish to.

If patients do not wish to discuss their illnesses, for whatever reason (cultural guidelines for decision-making, discomfort with the topics), honoring this wish also respects their autonomy. In a system whose current inability to preserve social and interpersonal ties[204] catapults the individual to the focus of the decision-making process,[205] the health care team should acknowledge those ties when the patient chooses to rely upon them. The "offering autonomy" approach is one model which attempts this type of discussion in the clinical setting.

5) Families can and often should aid the patient and the clinicians in any decision-making process.

They may have additional information the clinicians could use regarding the patient's history, or they may be able to remind the patient about past experiences or other responsibilities the patient may have otherwise forgotten in her time of stress.

6) The health care team should realize that the practitioner-patient relationship is often compromised by the status and power differentials of the participants and that cross-cultural medical care often exacerbates these differentials.

Information alone does not lead to the exercise of power. Patients must be encouraged to ask questions and to assert their individual needs and desires.

Societal Solutions

While changes in practitioner approach to cross-cultural issues will help deliver more culturally sensitive medicine, other solutions reflect more structural changes in the health care system. These solutions involve people other than practitioners; they include community members and leaders, public policy analysts, and legislators.

Recommendations:

1) The medical system should have more bicultural providers, translators, and others who are knowledgeable about the value systems of other cultures.

This would both improve communication in the therapeutic relationship and would anticipate possible conflicts in value, allowing those issues to be addressed before they escalate into a confrontation. This recommendation and implementation should arise both from within the medical establishment and from legislative mandates that are linked to federal and state funding of those medical centers with diverse populations.

2) Community leaders and other citizens should have increased involvement in policy development at the local level.

When a hospital develops a policy, such as informed consent procedures, community members who represent the cultures served by the facility should help contribute to development and review of such policies. Implementation of this suggestion would increase the quality of care as perceived by the community. Furthermore, it would help to reduce inter-cultural conflict by perhaps publicizing these policies and by maintaining these ties to the community through the individuals on the review board.

3) There should be further inquiry and research about the way in which decisions are made and the way families interact in the health care setting. This may include different decision-structures for different cultures.

It is only through this type of research that policies and structures can more accurately reflect the true nature of the human condition. Theoretical models only go so far in predicting human interaction in the medical setting. Research in this area would help to make the illness and therapeutic processes more tolerable and less conflict-ridden.[206]

Future Questions

Important questions for future discussion consider what cultural systems can lend to other communities in terms of their own strengths.

What can the Western model learn from the Chinese model? Many would argue that the patient's autonomy has assumed too large a role in medical decisions and that the family is often neglected.[207] Aren't the factors which will influence the decision (personality, values, situation) based on the inescapable influence that others have had and will have on the patient? Perhaps the medical system needs other, perhaps more fluid, models of ethics rather than an individual rights-based approach.[208] Caring ethics,[209] casuistry,[210] or virtue ethics[211] might provide different approaches.

At the same time, the Chinese model might consider the advantages of allowing individuals more power in decisions. The individuals have an interest in their own care, and disclosure may lead to decreased abuses of patients in disadvantageous positions. There is some evidence that discussions of patient autonomy are beginning to occur in modern China, especially in reference to euthanasia.[212] Additionally, the increased influence of Western biomedicine only furthers these discussions.

As Bernard Williams suggests, even totally separate and non-conflicting value systems can learn from each other. Different moral conceptions and even true-false claims help a person reflect on, question, and perhaps modify, the values of her own culture. Through mutual comparison and evaluation, differing value systems may create a more respectful and understanding global culture.

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[204] Fabrega, Horacio, Jr., "An Ethnomedical Perspective," p. 612.

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[205] Hardwig, John, "What About the Family," and Blustein, Jeffrey, "The Family in Medical Decisionmaking."

[206] Marshall, Patricia, "Anthropology and Bioethics," p. 54.

[207] See articles from Callahan, Pellegrino, Hardwig, Blustein, and Nelson.

[208] Trau, Mary Jane, "Relational Ethics in a Medical Context" article in publication with Cambridge Quarterly.

[209] Gilligan, Carol, In a Different Voice: Psychological Theory and Women's Development, (Cambridge, MA: Harvard University Press, 1982).

[210] Jonsen, Albert and Toulmin, S., The Abuse of Casuistry: A History of Moral Reasoning, (Berkeley: University of California Press, 1988).

[211] Pellegrino, Edmund and Thomasma, David, For the Patient's Good, The Restoration of Beneficence in Health Care.

[212] Pu, Shi Da, "Euthanasia in China: A Report," The Journal of Medicine and Philosophy 16 (1991): 131-138. See also Qui, Ren-Zong, "Medical Ethics and Chinese Culture," Transcultural Dimensions in Medical Ethics, eds. Pellegrino, Mazzarella, and Corsi, (Frederick, MD: University Publishing Group, 1993) and Qui, Ren-Zong, "Morality in Flux: Medical Ethics in the People's Republic of China," Kennedy Institute of Ethics Journal, (March, 1991), pp. 16-27.

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