

The Role of the Patient and the Family in Deciding to Forgoing Life-Support: Eastern and Western Perspectives

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A physician has just diagnosed in a mentally competent seventy-five-year-old man a cancer of the pancreas that predictably means for him a short and painful future life. The man has a wife and two adult children who have accompanied him to the physician's office. The physician now must make a choice: he can excuse the family from the room and proceed to report the diagnosis to the patient. He can then discuss treatment options with the patient in isolation including both aggressive, but unpromising therapy and forgoing such treatments to refer the patient to a local hospice. Second, he can find an opportunity to discuss the diagnosis and possible treatment options with the family when the patient is not present. Third, he can discuss these matters with both the patient and family present. The question is, which approach is preferable?

I. Western Approaches: The priority of the Individual

Western (especially American) and Taiwanese cultures have often been described



as having rather different responses to this situation. In the United States in the era of liberal biomedical ethics (since about 1970) and in other modern western cultures, the priority decision-maker is first, and foremost, the competent patient. In other cultures, in traditional Europe and Latin America and especially in the East, it would often be considered cruel and inhumane to impose this on the patient, especially when he is isolated from his family.ⁱ Presenting the information to the family (with or without the patient being present) is often described as the more common and the more preferred approach.

In a study at National Taiwan University in Taipei, Dr. Tai-Yuan Chiu and colleagues found truth-telling to patients one of the two most frequent ethical dilemmas in a palliative care setting.ⁱⁱ Truth-telling arose as an ethical issue in half the patients with pancreatic cancer. Perhaps it did not arise more often because all parties agreed not to tell the patient the diagnosis. The researchers say:

ⁱOle Doering, in his paper in this issue, [EDITOR: PLEASE VERIFY THAT DOERING'S PAPER APPEARS] makes clear that a similar pattern is appearing in Germany. He describes the evolution in Germany from its "extremely paternalistic past" to a pattern in which the will of the patient has become the determining factor. As he puts it, "If we can, we always have to ask the patient what he wants." Ole Doering, "The Meaning of Death and Dying: Confucian Reflections on Quality of life Assessment at the End of Life." *Formosan Journal of Medical Humanities*, forthcoming. See also Sass, Hans-Martin. "Images of Killing and Letting-Die, of Self-determination and Beneficence: The Ethical Debate on Advance Directives and Surrogate Decision Making in Germany. In Sass, Hans-Martin, Robert M. Veatch, and Rihito Kimura. *Advance Directives and Surrogate Decision Making in Health Care* Baltimore: The Johns Hopkins University Press, 1998, pp. 136-72.

ⁱⁱChiu, Tai-Yuan, Wen-Yu Hu, Shao-Yi Cheng, and Ching-Yu Chen. "Ethical Dilemmas in Palliative Care: A Study in Taiwan." *Journal of Medical Ethics* 26 (2000):353-57.



In oriental culture, it is common practice not to disclose the truth of the illness especially to a terminal cancer patient....

A. The priority of the competent patient as decision-maker

The Western, especially the American, ideology of liberal individualism gives priority to the competent patient as the primary decision-maker. Our legal and moral doctrine offers several reasons why this is so.

1. Consent doctrine requires that patient be informed

For the past three decades liberal political philosophy has imposed on medical decision-making a doctrine of informed consent that requires that patients be informed of their treatment options and be allowed to consent or refuse consent to proposed treatments.ⁱⁱⁱ Treating without the patient's consent is considered both unethical and illegal. Patients are the ones who should choose whether to fight a disease such as pancreatic cancer. No rational person would consent to the horrors of chemotherapy if he did not know he had cancer. Neither would the patient accept treatment in a hospice program. This belief in liberal individualism and the consent doctrine was not always dominant, even in the modern West. More traditional Hippocratic ethics that dominated Western medicine prior to the recent discovery of the age of liberalism by American medicine had no doctrine of consent. However, even in this earlier tradition the family played at most a minimal role. The physician was supposed to base his judgment on his beliefs about the patient's interests. The family still did not play a major role. However, since the rights movements of the 1960s, the focus has shifted to the choice of the individual patient. This trend has been so strong that some of us have even advocated abandoning talk of patient *consent* in favor of an even more robust patient

ⁱⁱⁱCobbs v. Grant 502 P.2d 1 (Cal. 1972); Canterbury v. Spence, 464 F. 2d 772 (D.C. Cir. 1972).
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choice.^{iv}

2. Patients have a right, grounded in autonomy to make choices about their care

Even if there were no law requiring the consent of the patient before treatment could begin, proponents of Western liberalism tend to hold a fundamental belief that patients have a right to make these choices. They see that a right grounded in the moral principle of autonomy. The principle of autonomy requires noninterference with people's choices based on their own personally held life plans. This moral commitment runs very deep in American culture. It is central to our founding ideology and key public documents even though it has appeared in medical ethics only quite recently.

Prior to about 1970 there was a strange absence of this moral commitment in American medicine. Although the public moral and legal commitment to respect the liberty of the individual traces back to the founding of the country, medicine was isolated from this ideology. Physicians, who were often not philosophically sophisticated or even informed, practiced medicine according to a Hippocratic idea that the physician's moral duty was to benefit the patient according to the physician's belief and judgment.^v Likewise, many lay people, particularly those from more authoritarian and less educated traditions accepted this paternalism rather passively. It was only with the rights movements of the 1960s that the practice of medicine began to be brought in line with the American commitment to liberty of the individual. Nevertheless, even in the era of

^{iv}Veatch, Robert M. "Abandoning Informed Consent." *Hastings Center Report* 25 (March-April 1995, No. 2):5-12.

^vEdelstein, Ludwig. "The Hippocratic Oath: Text, Translation and Interpretation." *Ancient Medicine: Selected Papers of Ludwig Edelstein*. Temkin, Owsei, and C. Lilian Temkin, editors. Baltimore, Maryland: The Johns Hopkins Press, 1967, pp. 3-64.



paternalistic medicine, the duty of the physician was perceived as being to the patient, not the family. Admittedly, sometimes the physician, absent the commitment to the autonomy of the patient, would attempt to benefit the patient gently by consulting with the family and revealing confidential information to them without the patient's permission, but the goal clearly was the welfare of the patient, not family welfare or family harmony.

3. Benefit/burden determinations are individual and subjective

The elevation of the patient to the role of central decision-maker became even more important as we realized that the decision to accept or forgo life-sustaining medical treatment is inherently subjective. The proper basis for deciding is the estimate of the benefits and burdens of possible treatments. At one time it was assumed, incorrectly, that because the physician was an expert on the science of medicine—including the facts of diagnosis and prognosis—he was also an expert on the value of various treatment interventions. We have now become aware that there is no basis for that assumption. Two different patients facing the same pancreatic cancer with the same prognosis can evaluate the alternatives quite differently. For one, the pain and nausea of aggressive chemotherapy is a small price to pay even though the chance of successful benefit are small. For another, the hospice alternative is clearly more attractive. Thus the benefit/burden calculation is not merely dependent on the diagnosis and prognosis. These must be taken into account, but the physician, even if he is the expert on these matters of medical knowledge, cannot from them alone determine which treatment is best for the patient. If the physician wants to know which treatment is better for a particular patient, the only way for him or her to know is going to be to ask the patient. For example, in the above-mentioned study at National Taiwan University, some patients and family valued alternative traditional Chinese treatments. Similarly, many American



patients value treatments that are not always the most valued by the provider.

4. Problem of confidentiality

The strategy of sharing the information with the family which then collaborates with the physician in deciding what is the best course for the patient poses another problem from the perspective of liberal individualism. There has long been a medical ethical principle that holds that medical information must be treated as confidential. It cannot be shared with third parties, at least without a law authorizing such disclosure. Hence, laws require reporting gun shot wounds and diagnosis of venereal disease and, in some jurisdictions, HIV. Otherwise disclosure, without the permission of the patient, is a breach of medical ethics if not the law.

If a physician reveals a patient's diagnosis to the family, that constitutes a disclosure of confidential patient information. Clearly, this is without the patient's permission since that patient himself does not know the information. Asking him for permission would alert him to the fact that a diagnosis has been rendered that the physician considers sufficiently grave that the physician needs to discuss it with the family. The only exception would be the special case in which the patient, in advance, has told the physician that he has no objection to disclosures to certain family members even before the patient learns of the diagnosis.

Thus, from the Western point of view, shaped by liberal political individualism, it is unacceptable for the physician to go to the family to discuss the patient's pancreatic cancer without the patient's permission.

B. Subsidiary role for the family

While the family is clearly subordinate to the individual patient in this modern Western individualist view, the family plays various important subsidiary roles.

1. Family is presumed first choice as surrogate

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First, the family is presumed to be the proper first choice as a surrogate decision-maker for patients who are not currently competent to decide for themselves. In the case of children, who, of course, are not legally competent to make their own medical decisions, the parents are presumed to be the guardians with legal authority to accept or refuse proposed medical treatment. No formal declaration of incompetency is needed. If pediatricians had to go to court every time they wanted to treat a child to get the parents appointed the child's legal guardian, they would spend all their time in courts. Instead, pediatricians routinely accept the authority of the parents as the legal and moral basis for making treatment decisions. Within some legal limits I will discuss momentarily, this authority extends to the right of parents to withhold or withdraw consent for life-prolonging medical interventions.

This authority is now also extended to the next-of-kin in cases of adults who are not mentally competent who need to have life-sustaining medical treatment made for them. At first some who readily conceded parental authority to make these decisions for their children, resisted giving family this authority in the case of a senile parent or other mentally impaired adult. This resistance is no largely overcome. In case after case in American law, the next-of-kin has been found to be the appropriate decision-maker for incompetent adults. This was true in several of our most famous cases including that of Karen Quinlan and Shirley Dinnerstein. In fact, in the Dinnerstein case, one involving a clearly impaired older woman whose two adult children were available to make a decision to forgo CPR for their mother, the court made clear that such cases need not go to the court.^{vi}

a. Substituted judgment is the preferred criterion

^{vi}In re Dinnerstein, 6 Mass. App. Ct. 466, 380 N.E.2d 134 (App. Ct. 1978).



However, in these cases in which family members assume decision-making roles for their incompetent family members, the liberal American tradition makes clear that the duty of the family is to make the decision based on their knowledge of what the patient would have chosen given his or her beliefs and values. It is not the interests or the beliefs of the family that are relevant; it is those of the patient. This information is obtained from formal written documents—now usually called “advance directives,” and from the family’s knowledge of what the patient has believed.⁵ This view is called the “substituted judgment standard.” It retains the priority of the patient’s individually held views over those of the family or the family decision-makers.

b. best interest is default only if patient’s wishes are not known

If, and only if, no knowledge can be obtained about the patient’s beliefs and values is the family given authority to attempt to make a judgment about what is best for the patient. This is called the “best interest standard.” Family decision-makers must do what is best for the patient based on their understanding of the *patient’s* best interest. They are still not permitted to take into account the interests of the family as a whole or of individual members in it. Parents are not even permitted to take into account the interests of other children, even if those interests conflict with those of the patient.

c. The principle of limited familial autonomy

While familial surrogates have the presumed authority to make decisions for their incompetent members—based first on substituted judgment and then on the best interest standard—they are given some discretion to draw on their own familial beliefs and values in interpreting, first, what the patient would want and, then, what they think is best for their family member. They are not held to the highest possible, objective standard in making these determinations. At the same time, they are not given unlimited discretion. I have taken to calling this special limited discretion for familial surrogates, *limited*



familial autonomy.^{vii} In effect the family is given an autonomy to draw on its own values in making the choice for the patient that is analogous to the autonomy of the patient. There is a critical difference, however. In the case of the autonomous patient making her own decision about whether to accept life-sustaining treatments the autonomy is unlimited, but in the case of the autonomous family, they are free to choose, but only within the range of reasonable choices. They need not choose the best possible option, but they must be within reason. There are some decisions so clearly against the wishes or interests of the patient that the family will not be permitted to make them. A judge will overrule. Thus even in liberal Western culture, there is a role for the family in medical decisionmaking even though that role is quite restricted.

2. Considerable worry about family choices

Even though the family is given this authority as the primary surrogate decision-makers, there is considerable worry about familial choices. There is concern about family members being malicious, foolish or unwilling to serve in the surrogate role. In extreme cases the courts or their agents—the child or incompetent adult protective agencies—will intervene and take custody of the incompetent one to see that the patient’s interests are served.

If the family member shows undue interest in the patient’s economic will, others will be alert to the possibility that the family is not giving its undivided attention to the patient’s interest. In other cases, the family acting in good faith may draw on unusual belief systems in ways that seem overwhelmingly to be contrary to the patient’s interests. Jehovah’s Witness and Christian Science parents may refuse blood or other treatments

^{vii}Veatch, Robert M. "Limits of Guardian Treatment Refusal: A Reasonableness Standard." *American Journal of Law and Medicine* 9 (4, Winter 1984):427-68.



even though those treatments will safely, simply, and surely produce cures while omitting them will lead to certain death. The courts uniformly over-rule familial decisions based on these views that the courts deem to be beyond reason.^{viii} Also, some family members for various reasons are unwilling to serve as patient surrogates and are released from these responsibilities.^{ix}

C. Historical/Cultural Roots of Western Liberal Individualism

It is worth asking why Western culture has elevated the status of the individual to this special place. It was not always the case. In earlier cultures, the group came before the individual. This was true in large degree even in historical Judaism, which had no principle of autonomy, no notion of the individual as primary decision-maker.

1. Christian roots of individualism

By contrast with the beginning of Christianity things began to change. Individual

^{viii}President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Deciding to Forego Life-Sustaining Treatment: Ethical, Medical, and Legal Issues in Treatment Decisions*. Washington, D.C.: U.S. Government Printing Office, 1983; Cantor, Norman. *Legal Frontiers of Death and Dying*. Bloomington, Indiana: Indiana University Press, 1987; Meisel, Alan. *The Right to Die. Second Edition*. New York, NY: Wiley; 1995; Veatch, Robert M. *Death, Dying, and the Biological Revolution*, Revised Edition. New Haven, Connecticut: Yale University Press, 1989. By way of contrast, competent and formerly competent adults who have expressed their refusal of treatment while competent have virtually unlimited rights of refusal even against the wishes of their families. See *In Re Maria Isabel Duran*. 2001 PA Super 52. In the Superior Court of Pennsylvania, Feb. 21, 2001, and more generally Meisel, Alan. "The Legal Consensus about Forgoing Life-Sustaining Treatment: Its Status and Its Prospects." *Kennedy Institute of Ethics Journal* 2 (1992):309-45.

^{ix}This was the case in *Saikewicz*. (*Superintendent of Belchertown State School v. Saikewicz*, 373. 728, 370 NE 2d 417 (1977).



Jews in Israel and then in surrounding areas of the Roman empire were asked to make individual commitment to a new religious community. A famous Biblical text has Jesus say that he has come to set a man against his father and daughter against her mother.^x In Christianity, believe it or not, this is considered a good outcome.

2. Becomes dominant view in modern Western liberal individualism

The beginnings of Western individualism in early Christian conversion decisions, received new emphasis in the Protestant reformation of the sixteenth century. In that social revolution, authority to read the scriptural texts and form moral and other evaluative judgments transferred to some degree from the priest to the lay person. While this view was attributed to the Martin Luther and John Calvin, the founders of the two major branches of European Protestantism, it is even more true in of the smaller, more radical groups of sectarians and mystics collectively referred to as the left-wing of the reformation.

a. Pluralism Makes Determination of Patient's Best Interest More Difficult

The Protestant Reformation not only empowers the individual lay person to form his or her own judgments about moral matters, it also creates a much more pluralistic, varied culture in which there exists side-by-side an enormous variation in beliefs and values. These variations mean that it is difficult to determine what is best for patients in matters such terminal illness treatment decisions. This makes it more and more difficult for physicians or others who do not know the patient very well to determine what is really in the patient's interest.

The decisionmaker must compare very subjective evaluations: whether the pain, suffering, and agony of chemotherapy are worth it, for instance. (In Taipei as well

^xMatthew 10:35



disagreement is reported between providers and family over the most valued place of care.^{xi}) These choices are heavily dependent on the unique value preferences of patients and cannot be known by physicians who are relative strangers to patients. Liberal pluralism makes it much less likely that physician or family will be able to guess at patient's best interest.

b. Empirical Evidence of Poor Judgment by Physicians and Others

There is empirical evidence of the difficulty that physicians and others face in attempting to determine what is best for patients. A series of empirical studies in the United States interview physicians who are caring for patients who are in positions in which critical decisions might soon need to be made regarding life-sustaining medical treatments. Researchers were able to ask the patients themselves while they were still competent whether they would want treatment provided and also ask various care givers for these patients what they believed their patients would want. The results were troublesome.

Physicians were able to guess at what the patient would have chosen at rates generally no better than chance. In various studies, depending on the question asked, physicians matched the patient's choice between 47% and 79% of the time.^{xii} Nurse and

^{xi}Chiu, Tai-Yuan, Wen-Yu Hu, Shao-Yi Cheng, and Ching-Yu Chen. "Ethical Dilemmas in Palliative Care: A Study in Taiwan." *Journal of Medical Ethics* 26 (2000):353-57.

^{xii}Seckler, Alison B., Diane E. Meier, Michael Mulvihill, et al. "Substituted Judgment: How Accurate Are Proxy Predictions?" *Annals of Internal Medicine* 115 (1991):92-98; Uhlmann, Richard F., Robert A. Pearlman, and Kevin C. Cain. "Physicians' and Spouses' Predictions of Elderly Patients' Resuscitation Preferences", *Journal of Gerontology: Medical Sciences* 43 (No. 8, 1988):M1115-121; Teno, J., Licks, S., Lynn, J., N. et al. "Do Advance Directives Provide Instructions That Direct Care?" *Journal of the American Geriatrics Society* 45 (April, March 28, 2007, C:\AA-WP60\LECTURES\04\TAI-CHUN\02-Dr. Robert Veatch



social workers do slightly better.^{xiii} When physicians were right 53% of the time, nurses and social workers guessed patients' real choices 55% of the time. Relatives of the patient were somewhat better than either physicians or nurses. They guessed patient preferences around two-thirds of the time.^{xiv} Family members did better if the patient selected the person who would act as the surrogate than if the physician did the selection,^{xv} but in no case were physicians, nurses, social workers, *or* family members

1997):508-12 [VERIFY]; Ouslander, Joseph G., Alexander J. Tymchuk, Rita Rahbar. "Health Care Decisions Among Elderly Long-term Care Residents and Their Potential Proxies", *Archives of Internal Medicine* 149 (June 1989):1367-1372.

^{xiii}Ouslander, Joseph G., Alexander J. Tymchuk, Rita Rahbar. "Health Care Decisions Among Elderly Long-term Care Residents and Their Potential Proxies", *Archives of Internal Medicine* 149 (June 1989):1367-1372.

^{xiv}Uhlmann, Richard F., Robert A. Pearlman, and Kevin C. Cain. "Physicians' and Spouses' Predictions of Elderly Patients' Resuscitation Preferences", *Journal of Gerontology: Medical Sciences* 43 (No. 8, 1988):M1115-121; Hare, Jan, Clara Pratt, Carrie Nelson. "Agreement Between Patients and Their Self-selected Surrogates on Difficult Medical Decisions." *Archives Internal Medicine* 12 (May 1992):1049-1054; Seckler, Alison B., Diane E. Meier, Michael Mulvihill, et al. "Substituted Judgment: How Accurate Are Proxy Predictions?" *Annals of Internal Medicine* 115 (1991):92-98; Ouslander, Joseph G., Alexander J. Tymchuk, Rita Rahbar. "Health Care Decisions Among Elderly Long-term Care Residents and Their Potential Proxies", *Archives of Internal Medicine* 149 (June 1989):1367-1372; Zweibel, Nancy R., and Christine K. Cassel. "Treatment Choices at the End of Life: A Comparison of Decisions by Older Patients and Their Physician-Selected Proxies." *Gerontologist* 29 (1989):615-21.

^{xv}Hare, Jan, Clara Pratt, Carrie Nelson. "Agreement Between Patients and Their Self-selected Surrogates on Difficult Medical Decisions." *Archives Internal Medicine* 12 (May 1992):1049-1054.

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much better than chance in guessing what patients would want.

That is true, at least in the United States where individuals have widely varying beliefs and values about terminal care. It might well be less true in a culture such as that of Taiwan where families might be more closely bonded, have better communication, or less variation about terminal care preferences. More fundamentally, however, this raises the question of what role the beliefs and values of the family ought to play in such decisions. While Western individualism sees the family as, at best, a substitute for the individual patient, Eastern cultures appear to tend to give the family a very different role.

II. Eastern Approaches: The Priority of the family

It is foolish for a Westerner to travel to Taiwan to talk about the values of various Eastern cultures and the role the family plays from these Eastern cultural perspectives. Nevertheless, I know just enough about Chinese and other Eastern cultures to know that it is wrong for me to assume my parochial Western views about the priority of the individual must prevail here as well. It is also the case that the scholarship on ancient Chinese medical ethics comes from both mainland and Taiwanese scholars and I may not fully understand subtleties of interpretation. Thus one of the goals of further scholarship in cross-cultural bioethics must be to learn more about the role the family is expected to play in these decisions and how the family interacts with the patient in modern Taiwan and in other places under ancient Chinese cultural influence.

In another paper in this issue of this journal [EDITOR PLEASE VERIFY THAT JING-BAO NIE'S PAPER IS INCLUDED] Chinese medical ethicist Jing-Bao Nie has warned that it is a mistake to assume that either Eastern or Western cultures are monolithic.^{xvi} Nothing said here in my attempt to sketch differences in patterns

^{xvi}Nie, Jing-Bao. "Is Informed Consent not Applicable in China? Intellectual Flaws of the 'Cultural Difference

Argument'." *Formosan Journal of Medical Humanities* forthcoming. Here he extends very persuasive arguments
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between Western liberal and Eastern roles for the family should be taken to conflict with the wisdom of his warnings. I have already attempted to show that not all Western medical ethics completely subordinates the role of the family in medical decisionmaking. In this section, while outlining a pattern of prominence for the family, I shall also note variations in Eastern views.

A. The presumption that family is primary decisionmaker

In Taiwan as well as on the mainland of China and other Eastern cultures more generally, the family has traditionally played a more primary role in making medical choices for critically ill patients. It is typical for the physician to talk with members of the family about a serious illness and that this can happen before or even in place of conversation directly with the patient. As described by Ren Zong Qiu with regard to practices on the mainland of China “Decisions involving the family still need to be made by all members of the family after consultation, not by any one individual.”^{xvii} This suggests a traditional role for the Chinese family that is different from the one I have described in Western culture. As East and West increase communication and exchange ideas as well as people, we need a better understanding of each others’ cultural patterns and beliefs.

B. Confucian virtues

One place I have looked to attempt to understand these differences is to the traditional Confucian virtues. In medicine two of the virtues in health care are

developed in Nie, Jing-Bao. “The Plurality of Chinese and American Medical Moralities: Toward an Interpretative Cross-Cultural Bioethics.” *Kennedy Institute of Ethics Journal* 10 (2000):239-60.

^{xvii}Qiu, Ren Zong. "Medical Ethics and Chinese Culture," in *Transcultural Dimensions in Medical Ethics*, ed. Edmund Pellegrino, University Publishing, 1992, p. 171 [pp. 155-174].

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compassion (*tz'u*) and humaneness (*jen*). These are not that different from contemporary medical ethical virtues in the West. The American Medical Association, for example, also lists two virtues for the physician. One seems, at least in translation to be identical: compassion. The other virtue for the AMA is “respect for human dignity.”^{xviii} Respect for human dignity may reflect more Western individualism than “humaneness” (*jen*), but Westerners, especially in feminist bioethics, also praise the virtue of humaneness.

However, Confucian medical virtues also sometimes include what in English is rendered “filial piety” and in Chinese is *hsiao*.^{xix} At least according to Paul Unschuld, the German scholar of Chinese medicine, this virtue makes medical care a family responsibility. This virtue of loyalty to family may help explain the prevalence of the family in medical decision-making in Chinese culture. Ren Zong Qiu has described a case with which he was familiar in mainland China. A family knows that further treatment of a terminally ill parent in intractable pain is pointless. Nevertheless the son and daughter cannot bring themselves to withdraw life-support for fear of violating filial piety.^{xx} On the other hand, Ren Zong Qiu and Da-Jie Jin also report a case from the city of Hanzhong in Shaanxi province in which the son and daughter of a 59-year-old woman

^{xviii}American Medical Association, Council on Ethical and Judicial Affairs. *Code of Medical Ethics: Current Opinions with Annotations, 1998-1999 Edition*. Chicago: American Medical Association, 1998, p. xiv.

^{xix}Unschuld, Paul U. "Confucianism." *Encyclopedia of Bioethics*. Edited by Warren T. Reich. New York: The Free Press, 1978, p. 200 [pp. 200-204].

^{xx}Qiu, Ren Zong. "Morality in Flux: Medical Ethics Dilemmas in the People's Republic of China." *Kennedy Institute of Ethics Journal* 1 (No. 1, 1991):26 [16-27].



suffering from cirrhosis prevail upon a physician, apparently without consulting the woman, to provide merciful euthanasia by injecting chlorpromazine.^{xxi}

I have also heard it said that filial piety is relevant in Chinese thought to determining the ideal character of the physician—as one who acts as if he were a family member. Whether this traditional Confucian norm is part of the modern physician’s understanding, it was, according to sources that reach us in the West,^{xxii} the ideal of the Confucian physician who was to act as if he were a member of the family. Thus, in 1895, Ho Ch’i-pin writes (in the epilogue to Hsü Yen-tso’s *I-ts’ ui ching-yen*) that “Whoever intends to protect his body and wants to serve his relatives has to have medical knowledge.”^{xxiii} It appears, at least to an outside observer, however, that, if the physician thinks of himself as if he were a family member, the role he approximates is more that of the father or of one with considerable authority. As one scholar of Chinese traditional medical ethics put it, “For physicians, to take charge of individual patients is central.”^{xxiv}

^{xxi}Qiu, Ren-Zong, and Da-Jie Jin. “Bioethics in China: 1989-1991.” <In:> Lustig, B. Andrew, et al., eds.; *Bioethics Yearbook, Volume 2: Regional Developments in Bioethics, 1989-1991*. Boston: Kluwer Academic; 1992: 360-61 [355-77].

^{xxii}Unschuld, Paul U. *Medical Ethics in Imperial China: A Study in Historical Anthropology*, Berkeley, California: University of California Press, 1979, p. 23, 109, 116.

^{xxiii}Text and translation in Unschuld, Paul U. *Medical Ethics in Imperial China: A Study in Historical Anthropology*, Berkeley, California: University of California Press, 1979, p. 109.

^{xxiv}Wu, Zhaohua. “Conflicts between Chinese Traditional Ethics and Bioethics.” *Cambridge Quarterly of Healthcare Ethics* 3 (1994):369 [367-71].



By contrast in Western medicine, even though humaneness and caring are virtues and sometimes the physician is described as a father figure, there are equally strong warnings against being too attached to one's patient. It is considered imprudent, even unethical, to treat member's of one's own family.^{xxv}

This central importance of the family in Chinese culture has been documented in traditional Japanese families as well. The emperor of Japan, who was once belief by the Japanese to be a deity, nevertheless apparently was not told by his physician and his family of his terminal medical diagnosis. Tomoaki Tsuchida, a cultural historian who teaches at Nanzan University in Nagoya, acknowledge that the family in Japan is losing its authority in medical decisionmaking to that of the individual. While individualistic Westerners hear this as encouraging, he describe it as an unfortunate loss of familial cohesion.^{xxvi}

III. Is There a Basis for Reconciliation?

Given these important differences in the patterns for decision-making for terminal care, some people perceive a need for reconciling these conflicting views. Not everyone is worried about these conflicts, however. It could simply be that one culture gives priority to the family while another gives it to the individual patient. If those in each culture are happy with that arrangement, then who should worry?

A. Need for resolving conflict

^{xxv}American Medical Association, Council on Ethical and Judicial Affairs. *Code of Medical Ethics: Current Opinions with Annotations, 1998-1999 Edition*. Chicago: American Medical Association, 1998, p. 155.

^{xxvi}Tsuchida, Tomoaki. "A Differing Perspective on Advance Directives." In *Advance Directives and Surrogate Decision Making in Health Care: United States, Germany, and Japan*. Edited by Hans-Martin Sass, Robert M. Veatch, and Rihito Kimura. Baltimore, MD: Johns Hopkins University Press, 1998, pp. 209-21.



While some pluralism in decision-making patterns is perfectly acceptable, assuming all the affected parties agree, there are cases of conflict where this consensus-based approach will prove inadequate.

1. Variations in Patterns within a Culture

In the first place, not every patient and family in a given culture will share the dominant cultural view about how decisions should be made. In a culture that presumes individual responsibility for health decisions, the physician usually cannot ask the patient whether she would prefer that a harsh diagnosis be given to the family instead without alerting the patient to the presence of a harsh diagnosis. This, of course, could be discussed in general terms when a patient and a physician first establish a relation, but often that only occurs at the time of a potentially critical diagnosis. If a patient is first seeing a specialist at the time of a critical diagnosis, the question of whether to transmit bad news first to relatives will be too threatening to provide the relief that some minority of patients might seek from attempt to transfer the decisions to the family. We have already noted that in some more traditional American families, particularly those whose beliefs and patterns were shaped prior to the rights movement of the last decades of the twentieth century, there is less commitment to the individual patient as the primary medical decisionmaker.

Likewise, some individuals in Eastern cultures may hold positions in which they expect to play this role. They are not satisfied to subordinate their role to that of the family. As Jing-Bao Nie argues in his essay in this issue of the journal, although many contemporary physicians in China may tend to follow the patterns here attributed to Eastern practice, this has not always been the practice in China. He cites Pian Que and Hua Tuo as two examples of great doctors who seemed always to tell their patients their diagnoses. Similarly, Ole Doering, in this issue of the journal, suggests that there are



interpretations of the Confucian virtue of filial piety that do not necessarily support the priority of the family and that some readings of Confucian thinking support moral self-determination.^{xxvii} Thus a modern Chinese who attempts to follow a model in which family decisions hold priority over individual choice may well confront members of his or her own culture who favor different, more paternalistic patterns. Thus even if health care were not cross-cultural, there would still be a need to resolve the tensions over the relative roles of the patient and family in critical medical decisions.

2. Cross-Cultural Medical Treatment

Second, health care increasingly takes place in a cross-cultural setting. If any of us who are not permanent residents of Taiwan attending this conference are unfortunate enough to require the services of a health professional while we are here, we will have to deal with providers who are not only strangers, but may value different cultural commitments. Patients from foreign cultures populate American hospitals in increasing numbers. In Washington, a high percentage of our patients are visitors or temporary residents. Those who reside permanently in Washington include many whose cultural commitments come from the cultures from which they migrated. The American doctor who has learned that the patient has a right to be informed about his diagnosis and must give informed consent to his treatments may accidentally offend his patient from an Asian culture. The doctor may be perceived as harsh, insensitive, and cruel if he follows what he has learned are the respectful, legally-required procedures.

In order to avoid perceived offense and insensitivity in cross-cultural health care, we need to have some cross-cultural default set of norms about the roles of the patient

^{xxvii}Ole Doering, "The Meaning of Death and Dying: Confucian Reflections on Quality of life Assessment at the End of Life." *Formosan Journal of Medical Humanities*, forthcoming.



and the family, norms that will prevail unless some alternative pattern is negotiated between provider and patient.

3. Desire for moral truth: a common morality

There is a more fundamental reason for seeking out a reconciliation of our decision-making priorities. At least some of us believe that on ethical matters such as these, there ought to be some more universal moral truth. Either patients have a right to be informed about their diagnoses and to consent (or refuse consent) to treatment or they do not. According to one option, subject to the qualifier that people have the right to select family surrogates to serve as their agents if they prefer, the patient has a moral entitlement to be informed. According to the other option, patients have a right to be spared the burdens of direct confrontation with their terminal illness and the decisions surrounding it. One or the other of these rights must prevail. That view must be our default position. That default can, perhaps, be supplanted by mutual agreement of provider and patient, but some default must be presumed until an alternative is chosen.

What appears to be at stake is two different conceptions of our rights as patients—the right to actively participate in our own treatment based on informed knowledge is inevitably in conflict with the right to be spared the harshness of direct confrontation with our terminal condition.

There is empirical support for the claim that there is a universal common morality that should govern behavior across cultures. A World Medical Association exists that attempts to articulate moral norms for various medical practices—a Declaration of Geneva for general medical practice and a Declaration of Helsinki for research medicine. These are codes that purport to articulate international norms for the practice of medicine. These professionally generated codes contain what may be a fatal flaw. They are not the products of public free deliberation, but rather written by a private group whose members



are limited to physicians. Most patients and most people working in biomedical ethics are, therefore, excluded from participation in their drafting and adoption. They should contain all the biases of a set of moral codes generated by a private group with selective membership. In this case, the membership includes physicians and excludes the patient perspective. Nevertheless, it reflects the belief that at least these physicians believe that there is one set of universal, abstract moral principles that govern across cultural boundaries.

Fortunately, there are similar international codifications that are true public documents in which all of us have opportunity to participate, at least indirectly. The Nuremberg trials produced such a set of norms for medical research with human subjects. There is a Universal Declaration of Human Rights subscribed to by many nations. These imply a belief that moral norms are not mere cultural constructs, but universal principles that are morally relevant to the behavior of all persons regardless of culture. Of course, different sets of social facts will still justify different behavior even if the same norms are applied, but, at least for those individuals who would prefer to be informed and make their own choices, it must be that they either do or do not have a right to their diagnosis and to consent or refuse consent to treatment choices. If there are reasons to believe that there is, or should be, a common morality, can we begin to construct a common morality for decisions during terminal illness?

B. Initial moves

We may be closer to the beginnings of the construction of a common morality for terminal care across cultures than we realize. First, from the West, even the most militant defender of patient autonomy should be willing to concede that it is permissible for a competent patient to transfer decision-making authority to others including family. Moreover, the next-of-kin is already presumed surrogate when the patient cannot speak



for himself or herself. The family's perception of what the patient wants or what is best for the patient governs, but there is an important, unresolved issue: if the family knows the patient's wishes, according to the Western consensus, the patient's own views take precedence over what the family feels would be best for the patient *or* what the family feels would be best for the family. There may not be anything resembling agreement on this from an Eastern perspective, however.

From the East, there may be evidence of a tentative willingness to consider giving the priority to individuals who wish this status. For example, the newly passed law in Japan to permit the use of brain-based death pronouncement when organs can be procured for transplant suggests an experiment in increasing the role of the patient himself or herself in at least one group of medical decisions. Although there is a general resistance to brain-death, for persons who are potential candidates for organ procurement for transplant, brain-death can be used to pronounce death provided both the family and the individual patient consent to the organ procurement and the patient, in addition, consents, to the use of the brain-death criteria.^{xxviii} The family's approval remains a necessary condition, but the patient herself must approve as well. In fact, the patient must give two approvals—the approval of the use of the brain-death criterion as well as the approval organ procurement. It would not be a great leap to extend this role for the patient to those who convey to the physicians that they wish to be informed and make their own medical decisions.

^{xxviii}“The Law Concerning Human Organ Transplants (The Law No. 104 in 1997). However, there is also considerable resistance to the new definition. See Hoshino, Kazumasa. “Legal Status of Brain Death in Japan: Why Many Japanese Do Not Accept "Brain Death" as a Definition of Death.” *Bioethics* 7 (2/3)(1993 Apr):234-238.



Likewise, some Taiwanese scholars in medical ethics appear to be open to considering some role for the autonomy of the individual patient in critical medical decisions. For example, Daniel Fu-Chang Tsai, of the National Taiwan University Hospital, has expressed some comfort with principle-based ethics of the West. He has even claimed that careful examination of ancient Chinese medical ethics reveals that, in Confucian medical ethics a “documented respect for a autonomy can be discerned.”^{xxix} Is this the overly-optimistic expression of a Taiwanese physician who has spent too much time in England? Is he one who expresses the Chinese goal of harmony when it comes to comparing Eastern and Western ethics for medicine? Or is this a real sign of the convergence of Chinese and Western thought?

Conclusion

Cultures must decide whether their default social policy should be one in which the individual is presumed to be the one who has primary decision-making authority or, alternatively, the default social policy should be one in which the family has this role. Whichever policy a culture chooses, it has the opportunity to create policies that respect the other priority for persons receiving health care in an environment in which the patient perceives that the wrong priority exists. When possible it is good for the culture to permit those policies. The remaining question is whether there is a moral imperative to move beyond these freedoms for those who dissent from their culture’s dominant policy to strive for cross-cultural resolution of the question of where the priority ought to be. I

^{xxix}Tsai, Daniel Fu-chang. “Ancient Chinese Medical Ethics and the Four Principles of Biomedical Ethics.”

Journal of Medical Ethics 25 (1999):317 [315-21]. For an interpretation of ancient medical ethics that gives much less room for a principle of autonomy see Qiu, Ren-Zong. “Medicine--The Art of Humaneness: On Ethics of Traditional Chinese Medicine.” *Journal of Medicine and Philosophy* 13 (1988):289 [277-300].



am convinced that this cross-cultural resolution is worth pursuing. Presumably, it will be a resolution that results from further exploration of the reasons why each culture has selected the priorities it has chosen.

