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A Discourse of Relationships in Bioethics: Patient Autonomy and End-of-Life Decision Making among Elderly Korean Americans

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A Discourse of Relationships in Bioethics: Patient Autonomy and End-of-Life Decision Making among Elderly Korean Americans

A two-year, multidisciplinary study (N = 800) was conducted on attitudes about end-of-life decision making among elderly individuals in four ethnic groups (African American, European American, Korean American, and Mexican American). On a quantitative survey, Korean Americans reported negative attitudes about the use of life-sustaining technology for themselves but positive attitudes about its use in general. This article reports on an interview with a 79-year-old typical Korean American respondent to explain the contradiction in the survey data. Expectations among elderly Korean Americans include protecting family members with a life-threatening illness from being informed of their diagnosis and prognosis, and doing everything to keep them alive. Two conclusions, one substantive and the other methodological, are drawn: First, the bioethics discourse on individual rights (patient

autonomy) is insufficient to explain the preferences of many Korean Americans and must be supplemented with a discourse on relationships. Second, the rigorous use of qualitative, narrative methods clarifies quantitative data and should not be dismissed as "anecdotal." [bioethics, end-of-life decision making, ethnicity, Asian Americans, qualitative methods, narrative]

I am the one who is going to die; so I don't control the situation.

—Mrs. Kim, 79 years old, Korean American immigrant

Although patient autonomy has been the dominant principle in bioethics in the United States for the past 25 years, consensus about its overriding importance is beginning to crumble.¹ Researchers have begun to recognize that the reigning conceptualization of autonomy is limited and illusory, and that social relationships may present an equally and sometimes more compelling framework for bioethics than individual rights (Callahan 1996; Gaylin 1996; Gaylin and Jennings 1996).² Empirical research by medical anthropologists has contributed support for such critiques. For example, not all patients expect or want full disclosure about their condition, and many prefer their families to receive and manage such information (Good et al. 1993; Gordon 1994; Gordon and Paci 1997; Orona et al. 1994).

Expectations about patient autonomy may cause confusion for some patients when their physician, an expert, solicits their opinion (Barnes et al. 1994; Koenig and Marshall 1994; Marshall et al. 1998). The mere suggestion of an aggressive or invasive treatment option such as mechanical ventilation may be interpreted by patients and their families as a sign of hope: Why else, they reason, would a doctor inflict pain? Moreover, patients may not explain their illness primarily or exclusively in terms of Western biomedicine. In traditional societies around the world, illness and disability are commonly attributed to factors such as a breach in social relationships surrounding the patient or supernatural causes. Such beliefs have implications for treatment that may conflict with biomedical procedures.³ Consequently, clinicians often need a better fit between North American bioethics principles and the preferences and decision-making styles of the diverse patients they serve (Barker 1992; Davis and Koenig 1996; Koenig and Gates-Williams 1995; Marshall 1992; Marshall et al. 1994; Muller 1994).

In the short history of bioethics as a discipline in the United States, patient autonomy earned its central role as a reaction to physician paternalism (Rothman 1991). It seems clear that patients are better situated than physicians to evaluate the appropriateness of available medical treatments in relation to their life circumstances. But the dilemmas faced in health-care decision making often are not framed as physicians versus patients. Rather, they are framed in terms of whom physicians should converse with: patients, their family, or both. The discourse around autonomy as the right of individual patients depicts patients as being alone and unaffected by relationships and, thus, undercuts an appreciation of the importance of patient-family interactions in medical decision making.⁴ In this article we argue that approaches to individual decision making that do not take relationships into account are inadequate. As Willard Gaylin writes, "Human beings are

products of their environment as well as its creators; therefore any consideration of the individual independent of his relationships and communities is self-defeating" (1996:44).

Serious consideration of a discourse of relationships may help bioethicists and clinicians avoid certain problems that arise when autonomy-based policies are applied at the end of life, such as in the use of advance care directives (ACDs). The Patient Self-Determination Act (PSDA) of 1991 requires that hospitals that receive federal funds inform patients about their right under existing state laws to create a living will or durable power of attorney for health care. Only a small percentage of Americans had an ACD in place when the law was passed, and proponents of the PSDA argued that increased public exposure would result in greater acceptance of ACDs (Fletcher 1989; Levin 1990; see also E. J. Emanuel and L. L. Emanuel 1990; L. L. Emanuel and E. J. Emanuel 1989; L. L. Emanuel et al. 1991).⁵ Currently, the number of Americans with ACDs remains low, and interventions designed to increase use of ACDs typically have failed to generate utilization rates of more than 20 percent in target populations (Hare and Nelson 1991; Jacobson et al. 1994; Sachs et al. 1992).

An even more compelling concern is that European Americans (whites) are much more likely to desire or possess advance care directives than other races or ethnicities (Blackhall et al. 1995; Caralis et al. 1993; Murphy et al. 1996; Sugarman et al. 1992; Teno et al. 1990). Such findings suggest that greater public awareness alone will not significantly increase the use of ACDs and that a better understanding of the cultural factors that affect their acceptance is needed.⁶ If bioethics policies are to meet the needs of patients whose values are different than those of the dominant white middle class,⁷ more must be known about the diverse clinical situations in which life-and-death decisions are made.

Methods

This article stems from the two-year study "Ethnicity and Attitudes toward Advance Care Directives," which surveyed 800 individuals, age 65 and over, residing in and around Los Angeles. The sample included 200 self-identified members in each of four ethnic groups: African American, European American, Korean American, and Mexican American. In year one, attitudes about end-of-life decision making were elicited in face-to-face interviews by ethnically matched interviewers who used an extensive survey protocol. In year two, in-depth ethnographic interviews, two hours in length, were then conducted with ten percent ($n = 80$) of the original sample, in the individual's preferred language, by ethnically matched anthropologist consultants.⁸ These interviews were treated as conversations, that is, as coconstructed speech events (Gubrium and Holstein 1994; Mishler 1986).⁹ The excerpts quoted in this article are presented in their actual sequence and in question-and-answer format, rather than as a monologue, to emphasize their co-construction by the interviewer.

A subsample in each ethnic group ($n = 20$) was selected for in-depth interviews by first creating a pool including only those individuals whose survey responses were typical for that ethnic group. In determining typicality, we paid attention particularly to dimensions of the survey on which the four ethnic groups showed statistically significant differences. Attitudes about patient autonomy were the core items of analysis, with a few additional items based on the unique response patterns for each ethnic group. Core items concerned physician truth telling

(Should the physician inform the patient about a diagnosis of metastatic cancer? About a terminal prognosis?) and medical decision making (Who should make a decision about the use of life-sustaining technology: the physician, family, or patient?). Of the 20 Korean Americans interviewed in depth, 18 were chosen from the typical case pool. Next, two atypical cases not in the pool were also selected to provide insight into the diversity within the Korean American sample.

One participant, Mrs. Hye-ran Kim, was a typical case. Her views represented those of the Korean American sample generally and were distinct from the views of the three other ethnic groups. Mrs. Kim's life story demonstrates how a family-centered approach to medical decision making is part of a broader Korean cultural pattern.¹⁰ Ideally, the roles and responsibilities of family members toward one another, rather than self-interest, constitute the paramount guide for moral action. Such values are modeled by parents to children, articulated as explicit principles of behavior, and reinforced through social sanctions to become an intrinsic part of one's character.

Mrs. Kim's case was also typical demographically: In 1990 the Korean population in the United States was 798,849 (U.S. Department of Commerce 1992). More than half of the Korean immigrants have settled on the West Coast; the largest population, an estimated 200,000, lives in Los Angeles (Bandon 1994). Among the four groups in our study, Korean Americans are the most recent to immigrate to the United States and tend to speak only Korean. Most are parents of highly skilled workers and professionals who entered from South Korea as adults under liberalized immigration policies established by Congress in 1965. Not surprisingly, the elderly Korean Americans were the least acculturated group in the study,¹¹ having been in this country an average of 12 years. Indeed, Mrs. Kim emigrated from Seoul 12 years prior to the study and spoke Korean only. Like most of the Korean Americans whom we interviewed, she was a permanent resident in California and was enrolled in Medi-Cal (the federal-state Medicaid program in California).¹²

The qualitative methods used by many medical anthropologists, including the sophisticated analysis of life stories and other narratives, are frequently overlooked or dismissed as "merely anecdotal" by quantitatively oriented clinical researchers. Our use of a rigorous multimethod design,¹³ however, made it possible to use narratives to explain an otherwise incomprehensible contradiction in the survey data: Although Korean Americans reported extremely negative attitudes about the use of life-sustaining technology (LST) for themselves, they were extremely positive about its use generally.¹⁴ Mrs. Kim explains this paradox: Although she did not want to be kept alive by LST, she believed that it is her children's duty to make the decision for her. In her view, family members are obligated to protect patients from learning that their illnesses are life threatening and must strive to keep patients alive "even one more day."

Korean American Attitudes about Patient Autonomy

A summary follows of Korean American attitudes about patient autonomy, based on a quantitative survey conducted during the first year of the study (Blackhall et al. 1995). A stepwise multiple logistic regression analysis showed that ethnicity is the most significant factor to account for differences in attitudes about patient autonomy reported by the four ethnic groups. Ethnicity accounted for more

TABLE 1
Respondents' answers to the question "Should the doctor tell the patient a diagnosis of metastatic cancer?" ($p < .001$).

| | Yes | No |
|--------------------|-----|-----|
| African Americans | 89% | 11% |
| European Americans | 87% | 13% |
| Mexican Americans | 65% | 35% |
| Korean Americans | 47% | 53% |

variability among the 800 respondents than did other demographic factors such as age, sex, religion, level of functional independence, level of education, and income.¹⁵

Among the groups surveyed, Korean Americans were the least likely to believe that patients should be told the truth about the diagnosis and prognosis of a serious illness. Less than half (47%) agreed that doctors should tell patients about a diagnosis of metastatic cancer (see Table 1). Only 35 percent agreed that doctors should tell patients that they are dying (see Table 2).

TABLE 2
Respondents' answers to the question "Should the doctor tell the patient that they are dying?" ($p < .001$).

| | Yes | No |
|--------------------|-----|-----|
| European Americans | 69% | 31% |
| African Americans | 63% | 37% |
| Mexican Americans | 48% | 52% |
| Korean Americans | 35% | 65% |

Korean Americans were most likely to believe that family members rather than patients should make decisions about the use of life-sustaining technology. Only 28 percent believed that patients should decide whether or not to use LST. A majority of Korean Americans (57%) believed that decisions about LST should be made exclusively by the family (see Table 3). (All differences cited above are statistically significant at the $p < .001$ level.)

TABLE 3
Respondents' answers to the question "Who should make the decision whether to put the patient on life support?" ($p < .001$).

| | The patient | The family | The doctor or other designated person |
|--------------------|-------------|------------|---------------------------------------|
| European Americans | 65% | 21% | 15% |
| African Americans | 60% | 26% | 15% |
| Mexican Americans | 41% | 46% | 14% |
| Korean Americans | 28% | 57% | 16% |

TABLE 4

Respondents' likelihood of possessing an advance care directive (ACD) ($p < .0001$).

| | |
|--------------------|-----|
| European Americans | 28% |
| Mexican Americans | 10% |
| African Americans | 2% |
| Korean Americans | 0% |

Contrary to stereotypes about Koreans, talking in advance about death, even their own deaths, is not completely prohibited. Elderly Korean Americans tend to accept death as a part of life: Virtually everyone we interviewed in year two of the study was a member of a mutual aid society (rotating credit union that functions as a burial society) and had already made funeral arrangements for themselves. But Korean Americans were the most likely of our study participants to agree that discussing death with a doctor could be dangerous to patients and that advance planning is not necessary because families will know what to do when the time comes (Murphy et al. 1996).

TABLE 5

Likelihood of possessing an advance care directive (ACD) among respondents who had knowledge of ACDs ($p < .001$).

| | |
|--------------------|-----|
| European Americans | 40% |
| Mexican Americans | 22% |
| African Americans | 17% |
| Korean Americans | 0% |

As reported in Murphy et al. 1996, Korean Americans were also least likely (0%) to possess an advance care directive (ACD) (see Table 4). Even among individuals who had knowledge of ACDs, Korean Americans were less likely than others to have an ACD in place. Of the 200 Korean Americans sampled in year one, only 20 had knowledge of ACDs, and of these, not one possessed a living will or a durable power of attorney (see Table 5).

The Case of Mrs. Kim: A Narrative Approach

A narrative approach made it possible to clarify Mrs. Kim's decision-making preferences and practices.¹⁶ We paid explicit attention to her use of Korean ethical principles or values such as *tori* (duty, literally, "the proper way of life")¹⁷ and *hyodo* (filial piety) through the stories she told about her experiences and expectations in health care settings. In Excerpt 1, for example, Mrs. Kim talks about her experience as a patient in which her family hid the fact of a cancer diagnosis. Seven years prior to the interview, Mrs. Kim discovered that she was having a vaginal discharge. She informed her youngest daughter-in-law about it and was taken to see a Western-style doctor who scheduled an operation.¹⁸ Before the operation took place, a period during which Mrs. Kim was taking traditional Chinese medicines, her discharge stopped. Mrs. Kim's story makes the point that families should not

inform a patient about a diagnosis of cancer, even though the patient is naturally curious. Her children, not she, were responsible for making the decision about her treatment.

Excerpt 1

Hye-ran Kim: So I told my children that I didn't need the operation because the discharge had stopped. My children told me that I should follow the doctor's instructions anyway; I should have the operation. After the operation, I was fine. For a year later they didn't tell me the truth. Then after two years, they disclosed that I had had cancer—the early stage. So the doctor took out half of my womb, not all.

Interviewer: Didn't you want to know [what your disease was]?

HRK: I would feel like a fool who didn't know enough to be curious about her own disease. [But] my children did a good thing for me, not a bad thing. If I had researched what it was, then it would be bad for everyone.

In Excerpt 2, Mrs. Kim explains in greater detail why it is unwise for patients to know their diagnoses. Disclosing a diagnosis of cancer to patients causes them to suffer and leads them to think obsessively about dying. When Mrs. Kim reflects upon her own case, she believes it was better to avoid such suffering.¹⁹

Excerpt 2

Int: If anyone in your family had cancer, do you think it would be good to tell the person about their disease?

HRK: Reflecting on my experience, if the patient were to know their disease, it would cause anguish. So I think it would be better not to inform the patient, and in that way the patient could pass away less fearfully. In the case of cancer, the patient cannot stop thinking about their own death: it is not good.

In Excerpt 3, Mrs. Kim comments on the use of life-sustaining technologies such as CPR or mechanical ventilation on patients with a terminal prognosis. Although Mrs. Kim has not witnessed the use of LST among her friends, she is emphatic that it is not good to prolong the life of a fatally ill person.

Excerpt 3

Int: Then, among your friends, was there anyone hospitalized for a serious disease?

HRK: So far, none. In the [Buddhist] temple,²⁰ I see 85-, 86-year-old people. They come to the temple even though they don't have much energy. But they still come to the temple.

Int: . . . Then you haven't known anyone living in bed with an oxygen mask for a long time?

HRK: None I know.

Int: According to American laws, as long as the patient's breathing is not stopped, the patient will remain alive regardless of the chance of resuscitation, whether the patient is conscious or not. Then, if the function of either the heart or the lung stops, by using CPR they keep the patient alive. How do you feel about this?

- HRK:** In my opinion, if the patient doesn't have a chance to live, then not using CPR would be better. If their life is prolonged, it causes burdens to the children at home. In hospital, it is less burdensome to the children. Attending the patient is a bother. I don't think that it is good for the fatally ill patient's life to be prolonged. The one who would pass away should pass away.

In Excerpt 4, Mrs. Kim discusses the difference between dying in the hospital and dying at home. Her concerns are expressed in terms of burdens placed on the children. In Korea, dying at home is preferred. But even though Mrs. Kim prefers to die at home, she sees no alternative to the American way of dying in the hospital. Mrs. Kim surprises the interviewer by suggesting, however, that dying in the hospital might be better than the Korean way because it relieves the family's responsibility to observe certain onerous rituals.

Excerpt 4

- Int:** In America, people die in the hospital. And in Korea people usually die at home. How do you think about this?
- HRK:** In Korea, people die at home. It is the custom. Allowing the patient to die at home is the children's responsibility. If the children let the patient die in the hospital, people would regard it as not being filial. The American way is good, isn't it?
- Int:** Do you like the American way better?
- HRK:** Yes, it doesn't bother the children so much. If the patient passes away in the hospital, they take the corpse to the morgue [*laughing*]. Then it looks too lonely for the dead person. In that case, no one goes to see the corpse in the hospital except occasionally. The family stays home. When I went to console a family who lost their mother, the family stayed comfortably at home.
- Int:** Should they stay up all night like in Korea?
- HRK:** Sure. Sometimes the Korean tradition works better in that case, but for being simple and practical, the American way is good too.
- Int:** Hypothetically—it is only “if”—what would you like at the time of your death?
- HRK:** If I died here, the American way would be applied, and if I died in Korea, then Korean ways should be followed. Don't you agree? How can people ignore the custom?
- Int:** Which would you like better?
- HRK:** I don't ask them to follow the Korean way if I die in America, do I?
- Int:** It means you prefer the Korean way.
- HRK:** Yes, but it is not possible. And in Korea, it is not possible to use the American way.²¹

In Excerpt 5, Mrs. Kim is presented with a scenario about the use of LST with a terminally ill cancer patient. She describes what are proper decisions for various family members. The excerpt exemplifies Mrs. Kim's view of patient autonomy. The dominant principle is the fulfillment of responsibilities embedded in family relationships: One must do one's best for a family member, whether parent, child, or spouse. One must do everything to avoid letting a family member die. Family members, not dying patients, are expected to make medical decisions.

Excerpt 5

- Int:* If the patient were your relative, then what kind of decision are you supposed to make?
- HRK:* If the patient were my child, then I would ask them to use the treatment in order to see my child alive even one more day.
- Int:* If the patient were your parent?
- HRK:* If my parent were aged and in such condition, well . . . as I would behave toward my child, I also would ask the same thing. I shouldn't let them die. I would try my best.
- Int:* If the patient were you, then what do you expect your children would decide for you?
- HRK:* If my children wanted to see me even one more day, then they might ask for the treatment. I am the one who is going to die; so I don't control the situation.
- Int:* When you think about the decision right now, would you want the treatment in order for your life to be extended if you were not conscious and had almost no hope to live?
- HRK:* I would rather pass away sooner, if by having my life extended it caused pain.
- Int:* But for others, you would ask for the treatment to extend the life?
- HRK:* In other cases, if the patient were either my child or my husband, then I would request the treatment in order to see them even a little longer.
- Int:* Then isn't that contradictory?
- HRK:* Although it's a contradiction, it's the right thing to do [tori]. Don't you think so? Would any children let their mother die without trying to save her by any means?

Seen against the background of the North American bioethics discourse on individual rights, Mrs. Kim's statement in the preceding excerpt is startling: "I am the one who is going to die; so I don't control the situation." Mrs. Kim appreciates the contradiction in wishing to avoid medically futile treatment while giving control to family members who are obligated to ask for it. But, she says, giving control to her family members is more important, that is, *tori*, "the right thing to do."

In Excerpt 6, Mrs. Kim elaborates on her views about the use of LST and ACDs. In common with other Korean Americans interviewed, Mrs. Kim expresses her willingness to accept death as a part of old age: "If I had such a terminal disease," she says, "then I would not have them use such treatment, since I have lived long enough." She further states that it is not good to sign an ACD in advance because the future cannot be known. She prefers her family to make any necessary decisions when the time comes.

Excerpt 6

- HRK:* If I were in a certain terminal condition, I would not want them to use it [LST] unless the treatment could make me live again. In my opinion, if I had such a terminal disease, then I would not have them use such treatment, since I have lived long enough.
- Int:* If there were a documented arrangement in which the potential patient's own decision were represented with their signature, would you want this arrangement?
- HRK:* I don't like to put my signature on anything in advance.

- Int:* Why?
HRK: You never know your future or your fate; so why decide in advance?
Int: Then you would want your family to decide later?
HRK: Yes. My family.

In Excerpt 7, the interviewer skillfully engages Mrs. Kim in a fuller consideration of ACDs, appealing to her sense of *tori*.

Excerpt 7

- Int:* Don't you think that such decision making might be burdensome for your family?
HRK: When I think about other people whose lives are extended by medication [whose lives otherwise would end], then I think that it is better for those patients to pass away gracefully instead of being treated with the medication. This is my opinion.
Int: But the hospital and the children of those patients have no choice, do they?
HRK: In the United States, by taking medication, terminal patients' lives are extended; so there are some patients whose lives are prolonged in that way for even a year.
Int: So the patient's own decision is important. When the patient is conscious, if they put their own signature on the paper saying that they don't want such treatment, then such treatment would be avoided later on.
HRK: But what if patients desire to live longer? When I observe patients here, I believe they all want to have such treatment.
Int: Then would you put your signature on such papers?
HRK: Sure. Why should my life be prolonged if there were no chance of living?
Int: But before you said you wanted your family to decide.
HRK: Well, if I got a terminal disease, I would rather pass away sooner, but I don't know how my children would deal with the situation even if I put my signature on the papers you described.

Several important points are raised here: First, Mrs. Kim actually reconsiders her position and says she would sign an ACD. Second, she appears to be influenced less by the argument based on *tori* ("Don't you think that such decision making might be burdensome for your family?") than one based on patient autonomy ("Well, if I got a terminal disease, I would rather pass away sooner."). Third, and most important for an accurate analysis of her narrative, however, Mrs. Kim affirms that her views in this part of the interview are only hypothetical ("But I don't know how my children would deal with the situation even if I put my signature on the papers you described"). She expects her children to interpret their *tori* as a mandate for using LST regardless of any statement that she might sign in advance.

In Excerpt 8, the interviewer and Mrs. Kim discuss the general impermissibility of talking to a person about his or her death. Such conversations are necessary, of course, for implementing the Patient Self-Determination Act and for completing ACDs. Mrs. Kim, like other Korean Americans we interviewed, states that it is inappropriate to talk to a person about his or her death. But she is willing to discuss

her own death in the interview because she draws a sophisticated distinction between “research” and “real life.”

Excerpt 8

- Int:* In order to use the paper that I mentioned, it is necessary to talk about death when the potential patient is still conscious and healthy. What do you think about this?
- HRK:* It is not good to talk about death in advance.
- Int:* Even for the old people?
- HRK:* I am also old. Although the person may be old, to talk on this issue in advance is not good. If asked to sign such papers, without knowing one's future, how could I sign them?
- Int:* Then you don't feel good talking about it with me?
- HRK:* Yes, that is fine. If it is about research and not real life, fine.

In Excerpt 9, Mrs. Kim is asked her opinion about how an ACD should be presented to a patient. She continues to speak hypothetically for purposes of the research interview, straddling a discourse of relationships (tori) or duty and a discourse of individual rights (patient autonomy). Mrs. Kim feels that the physician alone should offer the ACD. The document should be presented for her signature in a conversational style, in which her questions can be answered.

Excerpt 9

- Int:* Wouldn't some people feel reluctant to sign? What do you think about that?
- HRK:* Concerning the signing, if I became sick and were asked to do this, then I would do it, but now, since I don't know about my future, my signature would not apply.
- Int:* In that case, who should ask you to prepare the paperwork, to make decisions with a signature?
- HRK:* Can there be anyone else besides the doctor?
- Int:* How should the doctor approach you about it?
- HRK:* He should tell me that my disease is such and such, and ask me whether I like this way or that way. Then I might have my own preference. The process should be done in this question-and-answer style.

In Excerpt 10, Mrs. Kim once again makes clear the conditional and hypothetical nature of her comments.

Excerpt 10

- Int:* If the patient becomes critical and then unconscious, then how can the doctor know what the patient wants?
- HRK:* For me, I would say to the doctor that he should let me be: not use medicine.
- Int:* If you were not conscious, so you were not able to talk to your doctor like that, then what?
- HRK:* Then my sons should decide. If they want to see me even one more day, they would ask the doctor to use medicine, or if they want me to pass away peacefully, then they would decide the other way. It's up to them at that point.

- Int:* I have interviewed several Korean people on this issue, and the most difficult thing for me to understand is why the interviewees themselves wouldn't want treatment, but they would permit the treatment if the patients were their parents, in order to prolong their lives by even a day.
- HRK:* Sure. That is the right behavior for children. If people heard that a child had decided to end their parents' lives, they would regard the child's behavior as unfilial. It is okay for me to talk about myself, but that's because there are no children who say, "Let my mother pass away." If they should ask me to decide on my own, then I would prefer to pass away sooner without pain.

End-of-life decisions are more than a matter of personal conscience in the Korean American community. Children who "decided to end their parents' lives" would be judged harshly. In the interview, Mrs. Kim points out that she may freely hypothesize signing an advance care directive limiting end-of-life treatment because she is confident that her children will not say, "Let my mother pass away." She expects them to override any limitation on treatment to which their mother may have agreed in the ACD.

Implications of the Korean American Data: A Discourse of Relationships in Bioethics

Korean American attitudes about end-of-life decision making center on the importance of relationships and the responsibilities of family members rather than on patient autonomy. Such beliefs and practices derive from the traditional culture of Korea,²² which has much in common with the cultures of neighboring East Asian countries.²³ There is diversity among Korean Americans, much of it conditioned by adaptations made to life in the United States.²⁴ Mrs. Kim sounds content and secure in her relationship with her children. Although the attitudes she expresses are typical of our sample, not all of the Korean Americans we interviewed were as confident of their children's actual support as Mrs. Kim. Respondents frequently mentioned that economic pressures, arising especially when adult children and their spouses are employed full-time or live in another part of the country, contributed to intergenerational tensions and disappointments in fulfilling traditional Korean family ideals.

If children lack adequate financial resources, for example, they may be unable to request further treatment for their parents. Living arrangements are also critical. When children reside away from their parents, in Korea or elsewhere, it is very difficult for them to fulfill their traditional familial duties. Mrs. Kim assumes that the Korean American family will function much the same as in Korea. But notions such as filial piety are undergoing modification in the United States. Changing gender roles and economic stresses that result in women's fuller participation in the labor force make it difficult for wives, daughters-in-law, and other female kin to provide the same level of support for parents that was expected of them traditionally. Other institutional pressures, including the implementation of federal laws such as the Patient Self-Determination Act and state laws that limit how long a family may keep a corpse at home, also tend to force change. The result is not so much a wholesale switch from traditional Korean to white American middle-class

values as it is the creation of a new syncretic ethnic culture (Kim and Hurh 1993; Park 1989).

Koenig and Marshall (1994) argue that social scientists cannot "biopsy" attitudes or develop an "ethnic algorithm" that can be plugged into multicultural clinical situations and result in neat bioethical solutions. Every case is individual and circumstantial. Physicians need to negotiate with patients the treatments that will be acceptable for them, given a range of attitudes and practices within the patient's family and ethnic group. These negotiations require more than translation of autonomy-based bioethics policies across "language barriers" (Woloshin et al. 1995).²⁵ A physician's discussion of end-of-life treatment decisions directly with elderly Korean American patients rather than their family may itself be experienced by the patient as impolite or even a violation. A number of bioethicists and social scientists have begun to address how to negotiate cultural factors in clinical ethics consultation (Heitman 1994; Jecker et al. 1995; Marshall and Koenig 1996; Orr et al. 1995). Before employing the otherwise promising strategy of dialogue with patients about specific treatment choices (Benjamin 1990), physicians must first reckon with family relationships as a locus of ethical responsibility and decision making.²⁶

In other words, a discourse on relationships should supplement the discourse on individual rights. Although these discourses may seem to be mutually exclusive, as Mrs. Kim's case has shown, they are not. In its report *Deciding to Forego Life-Sustaining Treatment*, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research stresses that physician respect for the patient's values is one of the elements of good decision making: "The only time that the Commission finds it justified for a patient who could be informed and involved to be excluded is when that patient freely and knowingly transfers some decision-making authority to another" (1983:51).²⁷ We are not talking here about family members overriding the patient's autonomy. Most elderly Korean Americans in our study such as Mrs. Kim are saying, in effect, "Giving control to my family is the right thing. It is what I personally prefer and is my expression of autonomy."

NOTES

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1. The principle of patient autonomy holds that individuals have the right to control what happens to them and, in particular, to make informed decisions about their medical care (President's Commission 1983). According to this principle, patients should be told the truth about their diagnosis and prognosis, about the risks and benefits of proposed treatments, and they should have the right to make decisions based on this information (Beauchamp and Childress 1994).

2. Callahan's (1996) position in the bioethics debate about autonomy is that among the four principles in the "Georgetown mantra" (autonomy, beneficence, nonmaleficence, and justice), justice should sometimes take priority. This defies the conventional position held by Veatch (1996), for example, that no principle can trump autonomy (i.e., justify overcoming the individual's right to decide). In our study, we argue not that autonomy should be overcome but that it is more complicated than represented by either position. The Callahan-Veatch debate relates to a more general one about the proper foundations for ethics. Rawls (1971) argues that a just system is one in which laws about specific kinds of situations are based on the judgment of rational individuals in the "original position" (i.e., not presently in the situation themselves). In other words, Rawls finds it possible to imagine a lone individual whose decisions would be valid without regard to his or her immediate social relationships. Sandel (1982) argues against Rawls that relationships precede and constitute the person. Relationships make us who we are as individuals and define our interests. Obligations, therefore, are as central to our identity as rights. For a metacritique of Rawls and Sandel that analyzes their work in terms of the underlying universalist assumptions that they share, see Bauman 1993. There are many different sources in the West of a discourse on relationships, not just the communitarian one represented by Callahan, just as there are many different sources in Korea. Terms such as *relationships*, *the West*, *Korean culture*, and *ethnicity* gloss over distinctions among various epistemological and ontological sources in both cultures with regard to defining the person, morality, and the body.

3. See Landy 1977 for a general overview of the extensive cross-cultural literature. A summary of explanatory or causal models of illness appears in Csordas 1989. For a particularly clear example of conflict between biomedical and traditional causal models in an oncology case in Mexico, see Hunt 1993.

4. H. Lindemann Nelson and J. Lindemann Nelson (1995) address the problem of including families in medical decision making in mainstream North American contexts. They discuss a case in which a physician is stymied by a conflict between an elderly patient's right to privacy and her adult daughter's right to information as her mother's caretaker. The authors suggest that the conflict could be handled better if the physician were to engage the mother and daughter in a conversation about mutual obligations:

What's missing from this way of approaching the issue [i.e., the talk of individual rights] is any acknowledgment of the special claims people have on each other within a setting of intimacy. . . . The relations among the people involved can't easily be captured by talk of rights. Intimates belong to each other as well as to themselves, and this belonging has moral consequences. [Lindemann Nelson and Lindemann Nelson 1995:111]

5. According to a study published in 1987, only 9 percent of Americans had written advance care directives (Steiber 1987:72, cited in Emanuel et al. 1991:889). As a legislator introducing the PSDA in the House of Representatives stated, "Recent surveys show that only 9 to 15 percent of the population have executed advance directives. We believe this low number is due, in part, to lack of knowledge" (Levin 1990:E944).

6. Cultural factors may include not only traditional beliefs and values but distrust of the dominant medical system due to socioeconomic disparities and the experience of discrimination. We hope to address such issues in future reports from the study.

7. Lynn and Teno (1993) suggest that the meaning and usefulness of advance directives might be linked to a "middle-class" approach to health care. In Kelner's (1995) study of elderly Canadian patients ($N = 38$), almost all of whom were white Anglo-Saxons, more

than twice as many patients ($n = 27$) preferred to have a voice in decision making at the end of life than to delegate making such decisions ($n = 11$). Middle-class patients were more likely to prefer exercising control at the end of life than lower-class patients.

8. Participants were paid \$20 for the survey interview and \$25 for the in-depth ethnographic interview. The ethnographic interviews were audiotaped, transcribed verbatim into Korean, and translated into English. A semistructured interview format addressed a uniform set of domains across all four ethnic groups ($N = 80$). All questions were open-ended and conversational. The resulting qualitative data include illness narratives, life stories, and responses to hypothetical scenarios about medical decision making.

9. This methodological stance holds that the interviewer's understanding is built through the course of the interview and that negotiations of meaning occur between interviewer and interviewee. That which comes first in an interview provides a context for the interviewers to elicit for readers to interpret whatever follows. Excerpts from the interview transcript are numbered to facilitate the reader's sense of the sequential development of Mrs. Kim's narrative within the conversation.

10. Hauerwas and Burrell (1989) argue that considerations of moral character as revealed in life stories are important to ethical decision making. Mrs. Kim was raised in a wealthy family but during her marriage lived in hard times. Her husband was a civil servant when the Korean War broke out in 1950. He could not get a job for the next 20 years. Mrs. Kim began to peddle small goods so that she could feed and educate her children. Her life story emphasizes what she counts as ethically important:

Since he didn't work, I thought I needed to make a living for my children. I didn't know much and, inexperienced, I started to sell [*changsä*]. My work as a peddler paid well enough so that I could feed and educate my children. I did the work for 20 years. . . . I carried goods on my head and sold them. I fed and educated my children in that way. . . . My husband didn't earn any money at all for 20 years. He didn't have a job. At that time, while peddling, being old fashioned, I didn't reveal my peddling either to my husband or to my children. Wherever I encountered acquaintances while peddling, I felt more ashamed than if I were caught stealing. I made an effort to avoid people.

In peddling to provide necessities for her children, Mrs. Kim's moral action for more than 20 years is sustained by her parental duty (*tori*). Self-sacrifice is valued over protecting herself from shame. Mrs. Kim's moral actions are especially creditable because she protected her family from being directly confronted with the fact of her peddling, although it is hard to believe that her family never found out about it. The parallel with nondisclosure of an unfavorable diagnosis is striking: The Korean Americans we interviewed said that patients who are dying often know their diagnosis and prognosis through inference (*nunchi*), even though their families continue to protect them from learning the truth directly.

11. The Marin Acculturation Scale (Marin et al. 1987), which was translated into Korean for use with the Korean American sample, measures the degree to which individuals use their native language versus English in daily speaking, thinking, exposure to media, and socializing with others.

12. Mrs. Kim was interviewed in August 1994. State and federal policies currently threaten to end the entitlement of legal residents like Mrs. Kim to benefits including Social Security Income (SSI) and Medicaid.

13. Some recent discussions of the integration of qualitative and quantitative methods for clinical research include Brannen 1992, Carey 1993, Morse 1991, Stange et al. 1994, and Steckler et al. 1992.

14. An overwhelming majority of Korean Americans (78%) and Mexican Americans (79%) agreed with the statement "Life sustaining machines should never be stopped even if the patient appears to be dying because there is always the chance of a miracle." In sharp contrast, only 33 percent of African Americans and 29 percent of European Americans concurred with this statement. Given a scenario in which they were a patient in a coma with no

hope of recovery, very few Korean Americans (14%) wanted to be kept alive by CPR, a finding that was indistinguishable from that of European Americans (13%).

15. In the Mexican American sample, however, assimilation into the mainstream English-speaking culture was associated with more positive attitudes about autonomy, which was correlated with level of education and income.

16. There is growing emphasis on the importance of narratives or stories in clinical ethics consultation (see Gordon and Paci 1997; Hauerwas and Burrell 1989; Hunter 1991). See Kleinman's (1988) argument that listening to the illness narratives of patients should be a central feature of medical practice.

17. The word *tori* comes from the philosophical and ethical concept of the Tao, or The Way. It expresses a generalized principle of acting properly in human relationships.

18. The "Western doctors" seen by patients like Mrs. Kim are often Korean physicians practicing biomedicine.

19. Mrs. Kim told a related story, not presented here, concerning her consultation with an ophthalmologist about a growth on her eyelid. In that situation, a Korean-speaking nurse informed Mrs. Kim and her daughter-in-law that the growth on her eye was a cancer. Believing she had a fatal disease, Mrs. Kim began to put her affairs in order. Later the symptom disappeared and the diagnosis of cancer was acknowledged to be a mistake. Mrs. Kim was referring also to this story when she says that avoiding suffering is more important than satisfying the patient's curiosity.

20. Mrs. Kim is a practicing Buddhist, and many of her peers are Christian. Religious differences were not significant predictors of Korean American attitudes concerning patient autonomy, however. Mrs. Kim's attitudes reflect syncretism among Confucian, Buddhist, and folk or popular beliefs (e.g., about the role of Fate), as well as lessons drawn from her experiences in America. As Park points out, syncretism is common also among Korean Americans who are born-again Christians: "Their new Christian belief system verifies various aspects of traditional Korean culture. Being born again is an ongoing process in which individuals make choices between Korean influences of Confucianism, Buddhism, and shamanism and newly discovered American ideas represented by born again Christianity" (1989:287).

21. Koreans in the United States are well aware of state laws that limit how long a body may be kept and that make it impossible for them to have traditional funerals lasting several days at home.

22. Another Korean American interviewee (age 79, female) explained the reciprocal, intergenerational nature of *hyodo* (filial piety) by recounting a well-known folktale. It concerns the custom of *Koryo-jang* (Koryo-style funeral), which belongs to the medieval (Koryo) period of Korean history:

The fundamental basis of human life is filial piety [*hyodo*]. Those who adhere to this value of filial piety always try not to make their parents worry, and they follow their parents' advice well. . . . Filial piety is the fundamental basis of our human life. Filial piety travels along the family line. Certain families have devoted children generation after generation, as the old saying goes. . . . You know, there used to be a custom called "Koryo funeral" in Korea a long time ago. "Koryo funeral" is where a young father carries his elderly father on a *chikeh* [an A-shaped back frame] to abandon him deep in the mountain to his death. There was a young father who did that. While he was trudging to the mountain with his aged father in his A-frame on his back, his young son toddled and followed him. When his father unloaded his grandfather and also abandoned the A-frame there, the young boy said, "Father, let's also take the A-frame." "What for?" "Because I will need it to carry you here to abandon you when you are old." Hearing this, his father immediately changed his mind and took his father back home.

As you see in this story, everything goes down along the family line. You know, like father, like son. If you behave well for your parents in front of your children, your

children learn a good example, and, in their turn, they will do well for you. A tradition is to be carried on, you know.

23. Hoshino (1995) reports a virtually identical pattern of medical decision making in Japan. Bowman (1996) found many similarities in the end-of-life treatment preferences of elderly Chinese immigrants in Canada. See also Kleesing 1992, Muller and Desmond 1992, Nilchaikovit et al. 1993, and Yeo 1995.

24. The adaptation of Korean immigrants has been reported in studies in the following cities: Los Angeles (Hurh and Kim 1984, Park 1996), Chicago (Kim and Hurh 1993), New York (Park 1989, 1997), San Francisco (Kiefer et al. 1985), and Toronto (Berry et al. 1987).

25. The U.S. Department of Health and Human Services Office for Civil Rights designates more than 10 percent of the population in five states (California, New York, Texas, New Mexico, and Hawaii) as "Limited English Proficient" (LEP). Asian Pacific groups concentrated in Washington State and California comprise, respectively, 43 percent and 24 percent of the population designated as LEP in those states (Woloshin et al. 1995).

26. A parallel to the Korean American concepts of *tori* and *hyòdo* is presented by Freedman (1996), who discusses Jewish alternatives to bioethical decision making based in individual rights. In particular, the talmudic category of *morah*, an aspect of filial duty usually translated in English as "fear" but meaning the "subjugation of the family member's will to the parent," may be invoked by people who want their families to make decisions for them.

27. Similarly, the commission's earlier report *Making Health Care Decisions* (President's Commission 1982) draws attention to family relationships. The introduction, for example, states explicitly that "family members can be of great assistance in understanding information and making decisions" (1982:5).

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