Journal of Urban Health: Bulletin of the New York Academy of Medicine Vol. 78, No. 1, March 2001

Bioethics in a Different Tongue: The Case of Truth-Telling

Leslie J. Blackhall, Gelya Frank, Sheila Murphy,
and Vicki Michel

ABSTRACT *After a survey of 800 seniors from four different ethnic groups showed that Korean-American and Mexican-American subjects were much less likely than their European-American and African-American counterparts to believe that a patient should be told the truth about the diagnosis and prognosis of a terminal illness, we undertook an ethnographic study to look more deeply at attitudes and experiences of these respondents. European-American and African-American respondents were more likely to view truth-telling as empowering, enabling the patient to make choices, while the Korean-American and Mexican-American respondents were more likely to see the truth-telling as cruel, and even harmful, to the patients. Further differences were noted in how the truth should be told and even in definitions of what constitutes "truth" and "telling." Clinical and bioethics professionals should be aware of how their cultural and economic backgrounds influence the way they perceive ethical dilemmas and remember to make room for the diverse views of the populations they serve.*

INTRODUCTION

The study discussed in this paper began with the concern that much of bioethics was a top-down affair. The ethical problems surrounding end-of-life care and the solutions to these problems have been defined by professionals (like the authors) who are mainly white, middle-class people with advanced educational degrees and good (or at least decent) health insurance. When we looked at care at the end of life, we were concerned about excessive, burdensome, and futile medical technology and with the right to chose and, especially, to refuse treatments. Advance care directives were invented to address these problems, to ensure that patients' rights to refuse excessive care were preserved when they were so demented or comatose that they were unable to communicate, or even know, what those wishes were. Having decided what the problem was (too much futile care at the end of life) and the solution (advance care directives), much space then was devoted in the literature on bioethics to promoting these documents. However, most studies that look at the use of advance directives, even those studies with interventions designed to increase accessibility, show that relatively few people actually have completed a directive.[1–6]

The reasons why people do not complete advance directives are many and com-

---

Dr. Blackhall is a Fellow at the Pacific Center for Health Policy and Ethics, University of Southern California; Dr. Frank is at the University of Southern California Department of Occupational Medicine; Dr. Murphy is at the University of Southern California, Annenberg School of Communication; Ms. Michel is an Adjunct Professor at Loyola Law School, Los Angeles, California.

Correspondence: Leslie Blackhall, MD, 2415 Harmony Dr., Charlottesville, VA 22901. (E-mail: ljblackhall@sprynet.com)

plex, but one reason may be that the concerns of bioethics professionals about care at the end of life are not necessarily those most important to all segments of the population. For example, it is questionable whether patients, many of whom have no health insurance, who receive care at major urban hospitals are worried about getting too much medical care at the end of life. At these hospitals, their experience is more likely to be a fight for every bit of medical attention they receive, not fending off excessive care. Also, in the clinical experience of one of us (L.J.B.), it is not uncommon for patients and their families, particularly recent immigrants, to seem puzzled by, if not downright hostile to, attempts to involve them in end-of-life decisions.

Observations and reflections such as these led us to undertake a study to look at attitudes concerning end-of-life care among elderly people of different ethnicities. The purpose of this study was to examine and compare the attitudes and life experiences of people from African-American, European-American, Korean-American, and Mexican-American ethnic groups with respect to topics such as truth-telling, patient autonomy, advance care directives, and forgoing life support. This paper presents qualitative data from the portion of the study that dealt with the issue of truth-telling.

METHODS

This study used a combination of quantitative and qualitative research methodologies. After preliminary interviews, a review of the existing literature, and consultation with medical anthropologists who were expert in the groups we were studying, we developed a survey instrument designed to measure attitudes toward three main areas in end-of-life care: truth-telling and patient autonomy, advance decision making (such as advance care directives), and forgoing life support. This instrument then was translated into Spanish and Korean and pilot tested in all three languages. We recruited 200 subjects aged 65 and older from each of our four groups at 31 different senior citizen centers in the Los Angeles, California, area. (Elderly subjects were chosen because they were more likely to have personal experience caring for a seriously ill or dying loved one.)

Interviews were conducted by an interviewer of the same ethnicity and the language of choice of the subject was used. Methodology for this part of the study has been reported elsewhere.[7] With respect to truth-telling, our survey presented respondents with the case of a sick person who had been diagnosed with metastatic cancer by a doctor; we asked, “Should the doctor tell the patient that they have cancer?” In the next question, we stated that the doctor believed the patient would die of the cancer, and we asked, “Should the doctor tell the patient that he or she is going to die of the cancer?”

The second phase of this study began when the survey data were collected, and a preliminary analysis was completed. Medical anthropologists* with expertise in the areas regarding our four groups then conducted in-depth ethnographic interviews with 10% of the original group. The purpose of these interviews was to illuminate and enrich our understanding of the findings from the survey data, to help explain seeming contradictions in that data, and to allow our subjects to speak

---

*Jerry Wright, PhD; Anne Jennings, PhD; Sung Joo Ko, PhD; Kye Young Park, PhD; Carol Browner, PhD; Mabel Preloran, PhD; Gelya Frank, PhD; and Barbara Malcolm, MS.

their minds on issues of concern to them that we might have missed in our survey.

Subjects were selected using standard case sampling; however, in each group, we interviewed at least two subjects whose responses on the survey were atypical. This step was done to obtain insight into the diversity within groups. Within each group of typical or atypical cases, respondents were selected further for personal experiences with serious illness of self or family (as recorded in the survey), articulateness (as reported by survey interviewer), demographic characteristic (socioeconomic status, gender, and religion), and willingness to participate in a second interview. Participants were paid $25 for their time.

The qualitative interview guide was structured according to a standard set of domains and sections. Direct questions, conversational probes, and scenarios based on hypothetical cases were used to elicit open-ended responses about experiences and attitudes related to end-of-life care. All interviews (which averaged 1.5 hours long) were tape recorded and transcribed verbatim. Korean and Spanish language transcripts were translated into English, and the transcriptions and translations were checked and edited by the anthropologist who conducted the interview. In discussions among the principal investigators and the anthropologist interviewers, the interviews were read and analyzed for emerging themes.

RESULTS

The data from this survey have been published elsewhere[1];they are reviewed only briefly here. Almost all of the African-American and European-American subjects in our study believed that patients should be told the truth about a diagnosis of cancer (87% and 89%, respectively). Only 47% of Korean-Americans and 65% of Mexican-Americans believed in telling the truth about the diagnosis. With respect to telling the truth about a terminal prognosis, again the European-American and African-American respondents were much more likely to believe in open disclosure, with 63% of African-American and 69% of European-American subjects agreeing that a patient should be told. Only 33% of the Korean-American and 48% of the Mexican-American subjects agreed with telling a terminally ill patient about the patient's prognosis. Among the Mexican-American and Korean-American respondents, more years of education, higher income, younger age, and the ability to speak and read English predicted a positive attitude toward truth-telling.* Statistical analysis of the data, controlling for variables such as income, education, and access to care, revealed that ethnicity was the most important factor contributing to attitudes toward truth-telling.

Although large differences among the attitudes of our groups with respect to truth-telling are apparent from the survey data, the reasons for these differences cannot be determined from the survey responses alone. For this reason, in the ethnographic interviews, we repeated the case and asked not only whether should the patient be told, but also why. Why is it okay or not okay to tell? If it generally is

---

*This was particularly important in the Mexican-American group, which was divided into two groups, one that spoke and read English and got their news from English-language media. The group generally had a higher socioeconomic status. The attitudes of those in this group on the survey tended to look more like those of the European-American group. The second group of Mexican-Americans spoke, read, and thought in Spanish; had a generally lower socioeconomic status; and had attitudes that were more negative toward truth-telling. The Korean-American group was much less diverse. In general, this group had immigrated to Los Angeles from Korea more recently, and few of them spoke English.

not okay to tell, does that include you? Would you want to be kept in the dark? Have you ever had the experience of telling or not telling the truth to a relative or friend? The remainder of this article presents the results of our analysis of these ethnographic interviews; these results have not been published previously. The themes that emerged from the interviews are presented below; quotations from subjects are included to illustrate each point. In the sections that follow, subjects are identified by RP (research participant) number and ethnicity (EA, European-American; AA, African-American; MA, Mexican-American; KA, Korean-American).

Themes

Patient Autonomy: "Because It's Me" Among the European-American and African-American subjects, the theme that emerged most frequently was that patients in general and the subjects themselves should know the truth because, as RP 001 (EA) put it, "I'd want to know the worst because it's me; I would have to face it." For the participants holding this belief, information about their bodies is theirs to know, good or bad, simply because it is *their* body.

Although the knowledge of a terminal prognosis may be distressing, if you are not told, someone else is making decisions that are properly yours, and this lack of control is even more distressing than the bad news. As RP 008 (EA) said, "If there's anything wrong with me, tell me; it's my decision what to do. . . . I happen to be a person that wants to control my destiny as much as I can." Even if there is nothing that can be done to cure the disease, the knowledge itself is a form of power. To be the owner of your own body and life, you need to know about yourself. RP 259 (AA) stated this succinctly: "I want to know everything about me." It is a patient's right to know this information and the doctor's duty to tell it since "the person was intelligent enough to go to the doctor because he knew something was wrong, and he wanted to know what was wrong with him" (RP 263, AA). This complex of ideas, which is consistent with the patient autonomy model of bioethics, was mentioned by almost every African-American and European-American respondent interviewed. Many qualified their support for truth-telling with the idea that some people were not able to handle such information: "Some people, it would frighten them very much" (RP 022, EA). However, even those who worried that some were too fragile to hear the truth seemed to feel that most people could and should be told their diagnosis and prognosis, and that doctors should err on the side of truth-telling. The Korean-American and Mexican-American subjects, as we show below, were more likely to see truth-telling as cruel and potentially harmful rather than empowering, and they rarely mentioned the idea of a "right" to the truth.

You Know Anyway Related to the idea of truth as a right of the patient is the idea that patients will know, intuitively, that they are very sick or even dying, so there is no harm in telling them. RP 133 (EA) put it this way: "I think we have a sense of our bodies, and you know something's wrong, and it's better . . . to know exactly what," RP 108 (EA) said. "The person has a right to know, and I think internally a person has a feeling as to what the prognosis might be." The right to know is connected to the ability to know for these subjects. "It's my life, and I ought to know. 'Cause you got a feeling anyway. You know" (RP 301, AA). Ownership of your body gives you a right to truthful information; it also gives you the ability to sense this information before it is told. In comparison, some of the Korean-American and Mexican-American subjects agreed that the patient will know, but for these participants, this was a reason not to tell the patient the truth. "You don't have to tell the person about such a thing because, unless the person is a dummy, he or she will figure it out" (RP 451, KA).

Getting Your Things in Order One of the most common reasons given by our European-American respondents for wanting to know the truth about a terminal prognosis was so they could get their "things" in order. This rationale was much less common in our other groups. As RP 008 (EA) put it, doctors should tell the truth because "so many people don't have wills or anything else." "We feel that you need to take care of your business . . . make provisions for those who need to have provisions made for them. To me that's simply manly" (RP 22, EA). By getting your things in order, you can ensure that your family is cared for or, at the very least, prevent them from being burdened with complex financial matters after your death:

> You settle your affairs. You've got to have a trust or a will . . . and let your wife know where everything is, and go over the things with your kids and your family so you know that by the time I'm gone this is what's here and you do this and you do that. (RP 171, EA)

A subtext here is the desire to exert control in the face of an uncontrollable process, death. In this way, one could almost link the desire to complete a will prior to death with the desire to complete a living will prior to becoming incompetent. Both are attempts to extend the reach of one's control into situations in which, by definition, one otherwise is unable to exert any control. This interpretation is supported by the fact that, when our respondents were asked about living wills or durable power of attorney for health care, they frequently discussed the concepts of living trust and durable power of attorney for financial matters. At first, it seemed that our respondents were confusing the two concepts, but when pushed by our interviewers, it became clear that these two concepts simply were linked very tightly in their minds. Both types of document usually were completed in the same place (an attorney's office), often at the same time, and were saturated with complex meanings that revolved around the themes of mortality, burdensomeness, and control.

Get It Right with God When asked about truth-telling, some of our subjects discussed the issue as one having religious or spiritual significance. According to this idea, you should know the truth so that you can get it right with God. This theme was mentioned most frequently by our African-American respondents. If you know the truth, you have time to "get right with the good Lord . . . so when you die, your soul is saved" (RP 347, AA). "There are too many things a person has to do with his life at that point, to be in ignorance of his death . . . he has to go to his minister and . . . make whatever peace you have to make with your minister" (RP 252, AA). Even in the face of this knowledge, "When the Lord is with you, the devil can't do you no harm" (RP 289, AA).

Getting it right with God does not necessarily mean simply preparing your soul for death. If your doctor tells you that you have cancer, you have an opportunity to bring the problem to God, whose healing powers are greater than a doctor's. "I got another doctor, that's Doctor Jesus" (RP 201, AA). "[I would want him to tell me] because . . . I got another doctor I would go to that's the master of the universe, and let him tell me what to think about it" (RP 208, AA). If you know the truth, "you can prepare for it . . . ask your God [if you can live a longer life]" (RP 280, AA). "I want to know, can he help me; if he can't, tell me. If he can't help me, I go to the next person; that's the man above" (RP 364, AA). These answers reflect the belief that doctors are fallible and frequently can not know whether a patient will live or die. Only God is capable of having that kind of knowledge. As RP 289 (AA) said, "I wouldn't care if he told me because it wouldn't make it true. . . . I believe in the Lord just because he [the doctor] said you're going to die next week, I never will believe nothing like that." "Some [doctors] they say that, and they come out of it" (RP 280, AA). Doctors have one kind of knowledge and power; God another. "The doctors say what . . . the afflictions of the righteous is, but God delivers them out of it all" (RP 201, AA).

Interestingly, this theme of needing to know the truth so that one could become closer to God either for healing or for absolution simply was not mentioned by any of the subjects in the European-American group. This was a religiously diverse group that included (in roughly equal numbers) Protestants, Catholics, and Jews. Only one of our Korean-American subjects, a deeply religious convert to Christianity, mentioned this rationale: "Yes, I would [want to know the truth]. Then, I could repent for my sins before God" (RP 409, KA). Several of the Mexican-American subjects made similar comments: "I would not want to be deceived. . . . I would put myself in God's hands; I would repent for all my sins and for the bad things I have done" (RP 607, MA).

It Is Cruel to Tell In contrast to the European-American and African-American subjects, most of our Korean-American and Mexican-American subjects did not perceive the truth (especially the truth about a fatal prognosis) as empowering. Rather than envisioning the patient as an autonomous agent who needs information to make decisions and maintain control and dignity, the Mexican-American and Korean-American respondents viewed the patient as sick, weak, and in need of protection by the doctor and the family. Telling the truth in this context was seen as cruel. "Tell him [the patient] that he is getting better . . . because we should not be so cruel as to tell him, 'You are going to die, and it will be on such and such a day' " (RP 607, MA). Instead, it is kinder to "give him hope, console him . . . [so he can] always have hope that he will get better" (RP 607, MA).

> Anyway, the patient will die, so what is the use of saying you are going to die of cancer, right? The doctor should say, "You are okay; you will be fine. . . . Just take the medicine which will get you better." He shouldn't say that you have cancer so that you will die in a few months. Isn't that common sense? (RP 414, KA)

When one of our anthropologists commented to a Korean-American subject that, in America, most people were informed of their diagnosis and prognosis, the subject replied, "Yes, they are, because this allows patients to be prepared for death, but it must be very painful for those patients" (RP 447, KA). The benefit of "being prepared" here is seen as insufficient to outweigh the pain caused by knowledge of the truth. Of a son dying with liver cancer, one Korean-American respondent stated, "We just couldn't tell him because it was cruel" (RP 451, KA). She went on to illustrate this by telling how her son had guessed that he had cancer and had been very distressed:

> Holding on to me, he cried very, very sadly, saying, "Mother, I do not remember that I have done anything bad to others in my whole life. I do not know how I got stricken with this bad disease." . . . So, both he and I cried to the last drop of our tears.

This mother felt guilty that she had not been able to protect her son from the truth and did her best to make up for it: "After that, I comforted him so that he would not give up hope on himself."

Most of these subjects agreed not only that the truth should be withheld in general, but also that they would not want to know it themselves: "If they tell me . . . I have the terminal cancer, I will become more depressed because my life is coming to an end" (RP 605, MA). "I wouldn't [want to know]. . . . I would be afraid of dying" (RP 640, MA). One of our Korean-American subjects told us that, for many years, her children had hidden from her the knowledge that a surgical procedure was for cancer, and she stated, "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" (RP 480, KA, after a cone biopsy).

Many of the respondents, especially the Korean-American respondents, were aware that patients often come to know the truth even if they are not told directly. As one subject put it, "The patient in critical condition could get an idea of what she or he has by the doctor's attitude. However, there is a difference in knowing about one's disease from guessing and from confirmation by others. I feel I don't want to know about my impending death . . . without hope, one cannot live. . . . So anyone who says that she or he wants to know about having a disease is out of their minds because the knowing itself is painful. If the patients have more stress, their lives are shortened" (RP 414, KA). This is discussed in more detail below; here, we just note that knowing, or rather guessing, is better than being told directly because it allows for some ambiguity and for the possibility of hope.

If You Know You Die Faster The truth not only is distressing according to these respondents, but also it potentially is harmful, even fatal. "It's not good to tell people what's wrong with them because they die sooner. . . . I told the doctor not to tell him" (RP 605, MA). "If the spreading cancer didn't kill her, the fear would" (RP 640, MA). One respondent told us the story of his brother, who died of cancer in rural Mexico. The truth had been kept carefully from him until almost the end of his life, when he happened to come by a mirror and see himself. Seeing how wasted he looked, he realized his condition. After that, according to his brother, "He never recuperated. . . . That is when he gave up. I think that [noticing how grave the illness is] is very bad for a deathly ill patient. If he has something to pick him up, his life is prolonged" (RP 666, MA). One of our Korean-American subjects brought his wife from Seoul, Korea, to Sacramento, California, for treatment without informing her of her condition: "We kept it a tight secret. . . . If she knew, she would not be able to live longer because of the fear" (RP 447, KA).

Some People Can't Take It These themes, that the truth is cruel and harmful to patients, could be found in the transcripts of European-American and African-American subjects as well. Here, it almost always took the form of a statement that the truth is harmful for *some* people: "Some people just are not able, for whatever reason, to deal with unpleasant facts" (RP 007, EA). This almost always was qualified: "But, in general, I think you've got to level with people." (This statement was made by a man who felt that he could take it, but was not sure about his wife.) In this view, some people will not be able to cope after they receive such bad news; for these few, the truth is not empowering, but disabling. "Some people fall apart over nothing. And if the doctor knows the patient at all, he should be able to determine whether this person could handle it or not" (RP 259, AA). Some even admitted that they were one of the ones who couldn't take it: "I think it depends on the person. Some people can take the news better than others. . . . I'm a worrywart, and they tell me that; all positive things I would throw out of my mind" (RP 258, AA).

Not the Truth, but Hope Although superficially the attitudes of our Korean-American and Mexican-American subjects toward the truth seemed identical, there were differences between them. As we reviewed the data from our Mexican-American subjects, we were confused initially by what seemed to be a contradictory and ambiguous attitude toward the truth in many of the transcripts. For example, one of our Mexican-American subjects told us that, "It is my opinion that the truth must always be told [to everyone]. . . . I would want the doctor to tell me directly" (RP 658, MA). However, speaking of a cousin with cancer, she told this story:

> She suffered a lot . . . and always asked me, "Isn't it true that I have cancer?" I told her, "C'mon, what cancer? It's not cancer." . . . It would have been more suffering if she had known what she had. (RP 658, MA)

A respondent (RP 666, MA) (mentioned above), said, "I think that [noticing how grave the illness is] is very bad for a deathly ill patient," about his brother, who died after looking in a mirror. Further in that same transcript, this respondent said that, "Knowing the truth helps to make you feel better because you can look for a way to cheer up and not get to the end of the road like the doctors thought" (RP 666, MA). When asked by our anthropologist how a doctor should tell a patient the truth, he replied:

> He would tell you gently [saying], "Now, we are going to do everything in our hands so you feel better; however, we will not stop you from dying, but the 2 or 3 days you have left should be happy, and don't think about leaving because maybe it won't happen." (RP 666, MA)

That is, the doctor should tell the patient that the patient will die in 2 or 3 days, but at the same time tell the patient that maybe they aren't going to die at all.

Another subject (RP 730) answered an emphatic "Yes" to the truth-telling question and at first denied that people die faster when they are told ("Those are just rumors"), but later told us that the patient should not be told about the prognosis: "It's better not to tell them that part to encourage her so that she thinks she's going to live more than she will actually live" (RP 730, MA).

Some of these seeming contradictions simply may be an expression of the complexity of the subject. However, the perceived contradictory nature of these answers actually may be another variant of the top-down problem mentioned above. At the start of this study, the authors identified an ethical problem: truth-telling. The issue for us was whether the doctor should tell the truth. But, for these subjects, it appears that the more appropriate ethical category is "hope," and the issue is whether the doctor and family take away hope. Taking away hope is prohibited because it is cruel and because it makes the patient die faster. The truth is not the main issue; the truth can be told as long as it is told in such a way as not to remove hope. You can tell the patient that he or she is going to die as long as you tell the patient that he or she might not die. This is why telling the prognosis is so much worse than telling the diagnosis. As long as you tell the patient that the cancer can be cured, it is not so bad to tell the patient that they have cancer.

This interpretation is supported by two respondents in the Mexican-American group who actually had cancer. One of them had lung cancer. He agreed that people should be told the truth about their diagnosis, as he was. However, he admitted that he wouldn't want to know about a terminal prognosis: "No [don't tell me]. . . . It would torment me" (RP 615, MA). As far as could be determined from his description, he had only palliative (not curative) treatment (draining pleural effusions), but was convinced he was cured, or as he put it, "The tumor is dry" (RP 615, MA). (This case will be discussed in detail in a future paper.) The patient was told the truth about his diagnosis, but given hope.

Another respondent, with head and neck cancer, had a similar story. When asked if it was appropriate to tell the truth, he stated, "Oh, yes, because then [they could] connect me to a machine instead of having surgery and giving me therapy and X-rays. . . . He [the doctor] told me that it was going to get better with the machines" (RP 754, MA). Later, when asked about being told the prognosis, he said it was okay "for the doctor to tell me, but so that I won't become discouraged, to tell me that I am [going to live longer] even though I am not." Tell me the truth about my dying, but tell it in such a way that I do not have to face it without hope that I will live.

Hyodo and Nunchi For the Korean-American subjects, the issue of truth-telling was tied to the concepts of *hyodo* and *nunchi*. Hyodo is usually translated as filial piety. It refers to the duties that family members owe each other, particularly the duties that grown children owe to their parents. One of these duties, as noted above, is the duty of the family to take care of sick relatives, to take care of the relatives' physical needs, and to take care of the relatives' emotional needs by protecting them from the cruel and harmful truth. One example of good hyodo was mentioned above regarding the women who was kept in the dark about the reason for her cone biopsy (RP 480, KA). Another, more extreme, example was given by a subject whose wife was taken to open-heart surgery without her or her husband's knowledge: "She had it done without [us] knowing about it" (RP 419, KA). (Amazingly, this was done in a Los Angeles hospital.) The husband who told this story offered it as an example of good hyodo. Another of our Korean-American subjects stated that, "It is okay for me to know my disease, but what can I do for her [my wife] when she knows she has cancer? . . . It can't be possible; I can't do it. She would like to know . . . but she shouldn't [be informed]" (RP 576, KA). Since almost all of our respondents felt that doctors should check with the family prior to telling a patient the truth and because of hyodo the family cannot tell even those who wanted to know that they had cancer, it makes it very unlikely that the patient will be told the truth. This brings us to the concept of nunchi.

Nunchi is translated frequently as a guess or a hunch, but it might also be translated as nonverbal communication. Your daughter tells you that you are getting better, that nothing is seriously wrong with you. On the other hand, you feel very ill, and you are going to the doctor all the time to get medications intravenously. By nunchi, you figure out that you have cancer. This concept, therefore, relates to the idea that people often know their diagnosis and prognosis without being told. Several of our respondents stated that they would want to know the truth, but that they would not expect to be told. Instead, if they did come to know it, it would be by nunchi. When asked if he would want to know the truth, one subject replied, "I would like to know it; I should." Later, however, in response to the question, "Do you think a doctor should inform his patients who have incurable diseases regardless of their age?" he answered, "The doctor wouldn't tell it to his patient directly, but the patient would be aware of it indirectly. Patients have to know. . . . The patients somehow end up knowing it [by nunchi]" (RP 517, KA).

Another subject (RP 489) stated:

> As a patient, of course, I would want to know what I've got, but I doubt whether the doctor and the family would tell me the truth. They would not. If I were to hear the truth, the shock would be severe. . . . In terms of shock, not to inform seems better. . . . Telling you you have cancer, and it will be difficult to save your life gives a big shock, doesn't it? That's why the doctor should keep it a secret to the patient while informing the family of the fact; this may be the rule.

The patient wants to know, but does not expect that the doctor or family will tell him or her. If they care for the patient at all, they will try to keep it from him or her.

Learning by nunchi is more acceptable, as discussed above, because it leaves room for hope and perhaps because it comforts you to know that your doctor and children love you enough to try to give you hope. "If he told it to the patient, the patient would die more quickly. . . . I would try to know it, but he [the doctor] had better not tell me" (RP 563, KA). When speaking of their family members, even those who wanted to know the truth flatly stated that they would never tell a loved one:

> It is okay for me to know my disease, but what can I do for her [my wife] when she knows she has cancer? [How would I comfort her?] . . . It can't be possible, I can't do it. She would like to know . . . but she shouldn't [be informed]. (RP 576, KA)

What Does It Mean to Tell? This discussion of nunchi brings up the question, What does it mean to tell? As we can see from above, some of the Korean-American subjects who said they would like to be told actually meant they would like to learn the truth by nunchi, by nonverbal communication. The truth may also be told indirectly. One of our interviewers, who was from South America, told us how she learned that her mother had cancer. The doctor put her arm around her and said, "Your mother is very sick, and you must take very good care of her." The interviewer felt that this was a completely adequate disclosure. Later, when the mother was close to death, the doctor let slip the word "cancer," not to the mother, but to the interviewer's sister. Both felt that this had been a rude and insensitive thing to do.

A hospice patient from El Salvador of one of us (L.J.B.) provides another example of indirect communication. This man knew he had cancer; however, his family insisted he be shielded from the truth about his prognosis. The patient agreed with this. He asked that his son be in charge of learning all information and making all decisions about his care. However, the patient let the hospice team know that, before he died, he wanted to go back to El Salvador. A time came when he was told that he should go back to El Salvador. He was never told he was dying, but the information was conveyed. Even the patient mentioned above (RP 615, MA) with lung cancer, who insisted that his cancer was cured since the “tumor is dry,” by his action (making funeral plans, etc.) indicated that he had knowledge, on some level, about his actual situation.

This communication style is characteristic of what are sometimes referred to as “high-context” cultures. In a high-context culture, such as that of Korea, Japan, or Mexico, one is expected to infer from the social context many things without being told explicitly. Information is conveyed by nonverbal or indirect means. In low-context cultures, such as those of Germany and much of America, information is conveyed directly with detail and precision. Patients from low-context cultures who want to know the truth will expect to be told with this type of explicitness. The same is not necessarily true for patients from high-context cultures.

This may explain a situation that several oncologists have described to one of the authors (LJB). If a doctor is asked directly by a patient from a culture such as that of Korea, usually considered high context, about his prognosis, the oncologist answers frankly. At the next visit, the patient complains, “How could you have said that to me? Don’t you care about my feelings?” The patient is appalled that the doctor would be so direct. Instead of hearing, “You probably have 2 or 3 months to live,” he was expecting to hear something like, “We are doing everything we can, but you are very, very sick.”

Thus, people vary not only in whether they want to know the truth, but also in their understanding of what constitutes “telling.”

CONCLUSION

This study of 800 elderly subjects showed that major differences exist in the way people of different ethnicities view the issue of truth-telling. One of the core differences, around which many of the themes circled, is the question of how the truth affects the terminally ill patient. On one hand, the truth can be seen as an essential tool that allows the patient to maintain a sense of personal agency and control. Seen in this light, telling the truth, however painful, is empowering. On the other hand, the truth can be seen as traumatic and demoralizing, sapping the patient of hope and the will to live. For those who hold this view, truth-telling is an act of cruelty.

In fact, many, if not most, of our subjects held both views. They differed in the relative weight given to each view. In weighing the positive benefits of the truth versus its potential to harm, the deciding factor seems to be the way the self is understood. Are we mainly autonomous agents whose dignity and worth come from the individual choices we make with our lives, or is our most important characteristic the web of social relations in which we exist? If we hold the former view (as most of our African-American and European-American respondents did), then lack of access to the truth is almost dehumanizing since it strips us of our ability to make choices, without which we are something less than fully human. If, however, we tend to see ourselves not as individuals, but as a part of a larger social network (as was more common in the Mexican-American and Korean-American groups), then the notion of personal choice loses something of its force, and we may expect that those close to us will act on our behalf to protect and nurture us in our time of need.

The second meta-theme that emerged from these data has to do with the many meanings of telling. When we began this study, we assumed that there were two possibilities: The truth could be told to or withheld from the patient. This is how the survey instrument was designed; respondents had to answer yes or no to questions about telling the diagnosis and prognosis to a patient with terminal cancer. However, many of our subjects, particularly in the Mexican-American and Korean-American groups, had a view with more nuances of how the patient could be told, or could come to know, the truth. According to these respondents, the truth could be told vaguely, partially; could be understood without telling, by context and hints; or could be known by nunchi. These types of telling allow for ambiguity and therefore for hope. This adds another layer of complexity to the issue of truth-telling and calls into question not only whether, but also how, we should tell the truth and even what telling and the truth mean.

Limitations to these data should be noted. As with all qualitative studies, a relatively small number of subjects were interviewed (80, or 10% of the 800 survey respondents). Although we attempted to pick subjects for the ethnographic interviews whose survey responses were consonant with the norm of their ethnic group, as well as some who disagreed for comparison, it is inevitable that some points of view were not represented. Furthermore, this project focused on elderly people from only four ethnic groups in urban Southern California. We cannot know how other age or ethnic groups or those in more rural locations would respond.

Finally, it is important to note the danger of stereotyping. Data like these that compare the differences in attitudes among groups cannot be used to predict the attitudes of any individual within one of those groups. People can, and frequently do, disagree with the norms of their culture. However, if we do not try to understand how people of different backgrounds think, we will fail to examine our most deeply held beliefs. Instead, we may end up thinking that these unexamined attitudes are self-evident, in need of no justification: common sense. To some degree, this may have happened with bioethics. Beliefs commonly held in the European-American culture about individuality, self-determination, and the importance of maintaining control too often have been treated as if they were universal ethical principles. Only by allowing diverse voices to speak, and hearing the sometimes surprising things they have to say, can we ensure that we are addressing the real concerns of the communities we serve.

ACKNOWLEDGEMENT

We acknowledge the Pacific Center for Health Policy and Ethics and Alexander Capron and David Goldstein for their assistance with this project. Funding for this project was provided by the Agency for Health Care Policy and Research (R01-HS07001).

REFERENCES

1. Hare J, Nelson C. Will outpatients complete living wills? A comparison of two interventions. *J Gen Intern Med.* 1991;6:41–46.
2. Sachs GA, Stocking CB, Miles SH. Empowering the older patient? A randomized controlled trial to increase discussion and use of advance directives. *J Am Geriatric Soc.* 1992;40:269–273.
3. Caralis PV, Davis B, Wright K, Marcial E. The Influence of ethnicity and race on attitudes

toward advance directives, life-prolonging treatments and euthanasia. *J Clin Ethics*. 1993;4:155–166.

4. Teno JM, Fleishman J, Brock DW, Mor V. The use of Formal Prior Directives among patients with HIV-related diseases. *J Gen Intern Med*. 1990;5:490–494.
5. Sugarman J, Weinberger M, Samsa G. Factors associated with veterans' decisions about living wills. *Arch Intern Med*. 1992;152:343–347.
6. Murphy ST, Palmer JM, Aze S, Frank G, Michel V, Blackhall LJ. Ethnicity and advance care directives. *J Law Med Ethics*. 1996;24:108–117.
7. Blackhall LJ, Murphy S, Frank G, Michel V, Azen S. Ethnicity and attitudes toward patient autonomy. *JAMA*. 1995;274:820–825.