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Racial, Cultural, and Ethnic Factors Affecting the Quality of End-of-Life Care in California:

Supplemental Materials

March 2007

Racial, Cultural, and Ethnic Factors Affecting the Quality of End-of-Life Care in California:
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by

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Summary of Methods

The authors obtained the information necessary for synthesizing this report by engaging in the activities summarized below. All activities received Institutional Review Board (IRB) approval from Stanford University's Human Research Protection Program (HRPP) Research Compliance Office (on file). Details for each activity are available on request.

In summary, the authors:

1. Used a comprehensive systematic review of qualitative and quantitative literature on core end-of-life issues, conducted by the Agency for Healthcare Quality and Research[1];

Findings were used from the evidence report generated by investigators at the VA Greater Los Angeles Healthcare System; Southern California Evidence-Based Practice Center and RAND Health; Washington Home Center for Palliative Care Research, Washington, DC; Agency for Health Care Research and Quality; Johns Hopkins University; and City of Hope, Duarte, California. They studied the resulting document that analyzed 911 articles in the U.S. literature, focusing on studies relating to ethnic/racial or cultural factors or those conducted in California. Relevant articles were included in discussion of core issues for this report.

2. Analyzed 2004 Death Public-Use Files from the California Department of Health Services, Office of Health Information and Research;

Data Source. Data on deaths were collected from death certificates and abstracted by staff of the California Department of Health Services, Office of Health Information and Research. The authors accessed this data for deaths in 2004 and reported crude death rates to show the actual rate of dying in a given population. They calculated age-adjusted death rates using U.S. Bureau of the Census (2000) standard population proportions to develop a weighted average rate and presented age-adjusted rates as a single, summary measure. The cause of death data and trajectory calculations presented in this report are based on the vital statistics records for 2004 using ICD-10 codes I60–I69 as defined by the National Center for Health Statistics. The authors analyzed deaths by place of residence, including only those deaths occurring among residents of California, regardless of the place of death. The source data collected by the state reported race and ethnicity based on the following race/ethnic groups: American Indian, Asian, Black, Pacific Islander, White, and Hispanic origin of decedents. They did not include deaths by persons coded as other or as representing two or more racial groups. State data are collected by disaggregated racial/ethnic groups and were analyzed for Asian and Hispanic groups. The Office of Health Information and Research warns that "caution should be exercised in the interpretation of mortality data by race/ethnicity. Misclassification of race/ethnicity on death certificates may contribute to death rates that may be understated among American Indians, Asians, Hispanics, and Pacific Islanders."

Analysis. Descriptive and bivariate analyses of study variables were performed using STATA (Stata Corporation, College Station, Texas).

3. Conducted focus groups with health care providers in Los Angeles and Fresno;

The services of Lake Research Associates (LRA) were used to recruit, videotape, and moderate focus groups. LRA transcribed the discussions and provided the preliminary report presented

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[1] Lorenz, K., J. Lynn, S.C. Morton, et al. End-of-Life Care and Outcomes. Evidence Report/Technology Assessment No. 110. Chapter 3: Results. (Prepared by the Southern California Evidence-based Practice Center, under Contract No. 290-02-0003.) AHRQ Publication No. 05-E004-2. Rockville, MD: Agency for Healthcare Research and Quality. December 2004.

in Appendix C. Participants were identified from publicly available lists of hospital, hospice, and other health care institution rosters as well as known professional contacts of the PI and her advisory group. Interviews and focus groups emphasized three core areas: decision making at the end of life; pain and symptom management; and communication). The focus group sessions took place at professional focus group facilities in Fresno and Los Angeles and lasted approximately 120 minutes. Excerpts that illustrate the core issues defined in this report were then selected from transcripts. Future analysis will include grounded theory and narrative analytic methods and will be reported later.

4. Conducted original survey research with pharmacies in Fresno, California, including geocoded data available through GIS-based ArcEditor and Business Analyst software, respectively (ESRI, Redlands, CA);

Institutional review board approval was obtained from the Stanford University Medical School. This survey study used two data sources: (1) pharmacists in chain and independent pharmacies and (2) 2000 U.S. Bureau of the Census data and 2005 to 2010 projected data as available through GIS-based ArcEditor and Business Analyst software, respectively.

Sampling Method

Pharmacies were identified, using Superpages.com, based on their telephone number listing and a Fresno, CA address (with the exception of two pharmacies located in Clovis). These pharmacies were mapped and defined as either chain or independent. They were further defined as being located within a minority (more than 70 percent minority) or non-minority (more than 70 percent white) neighborhood. Neighborhoods were defined as being within a 1.0 mile radius of a pharmacy location.

All 102 pharmacies listed on Superpages.com were contacted by phone to insure their phone numbers were correct and to collect fax numbers for future use. After these initial phone calls, the total number of pharmacies was reduced to 84, due to duplications, pharmacies being out of business, and erroneous listings.

Pharmacy manager names were obtained by phone for each of the 84 pharmacies. Letters were mailed to all 84 pharmacy managers asking for permission to contact the pharmacists at their stores. For chain pharmacies, division managers responsible for the Fresno area were contacted and asked to grant permission for the authors to contact all of their stores in Fresno. Thus, a division manager's signature served as a proxy for individual pharmacy managers of the same chain. Division managers usually consulted with their corporate lawyers prior to approving the study.

Once permission was granted via the signature of the pharmacy manager, individual pharmacists were contacted. The authors obtained oral informed consent and then administered a 10-minute questionnaire (see attached) either over the phone (conducted by researcher) or by fax, depending on pharmacist preference. Most questionnaires were completed by the pharmacy managers.

If pharmacy managers did not respond to the initial request for permission to contact their pharmacies, they were contacted via a follow-up phone call approximately one month after the initial permission request was sent.

Data Collection and Measures

The research team designed the questionnaire, with assistance from pharmacists who were not directly involved in the study. It was then pilot-tested at several pharmacies in the San Francisco/East Bay Area. The final version contained three main components: pharmacy demographics, inventory, and supply. The sections on demographics and inventory were designed to assess pharmacy characteristics beyond the supply of pain medications. For example, the authors collected data regarding pharmacist perceptions of the demographics of their customer base, the breadth of the geographic area served by their pharmacy, inventory procedures, decision making with regard to what medications are ordered, and their protocol if a patient wants to fill a prescription for a medication the pharmacy does not have in stock. The final section of the questionnaire, supply, was based largely on the questions asked in previous studies. Using the WHO's Pain Relief Ladder as a guide (See Appendix B.), pharmacists were asked about the current availability of 15 common pain medications at their pharmacy. The pain medications were consistent with the published pain guidelines and recommendations for use of morphine and alternative opioids in cancer pain. The following three categories of pain medications were identified: long-acting (i.e., controlled release oxycodone, controlled release morphine, Fentanyl, levorphanol, and methadone), short-acting (i.e., immediate release oxycodone, immediate release morphine, hydromorphone, butorphanol, and meperidine), or combination products (i.e., propoxyphene, acetaminophen and hydrocodone, acetaminophen and oxycodone, and oxycodone terephthalate). The ad hoc technique for coding pain medication availability used by Morrison et al and Green et al was used in this study. Thus, if at least one of the drugs in each category (controlled release, immediate release, and combination product) was available, then the category was coded as 1=available; otherwise, it was coded as 0=unavailable for each pharmacy. Further, if a pharmacy had availability in all three categories of pain medications, then the pain medication supply was coded as 1=sufficient supply; otherwise it was coded as 0=insufficient supply. Hence, a pharmacy may have certain pain medications available, but by this technique they must offer a spectrum of medications to be coded as having sufficient supply.

Statistical Analyses

All calculations and statistical analyses were performed using procedures in STATA (Stata Corporation, College Station, Texas). Descriptive statistics and bivariate analyses for presence of a pharmacy, pain medication supply, neighborhood median age, median income, prescription drug expenditures, ethnic composition, and pharmacy type were computed at the pharmacy level. The authors constructed models for multivariate analysis to determine odds ratios for variables of interest.

5. Reviewed curriculum offerings used to meet the AB 487 mandate;

The website of the California Medical Board was examined to obtain a list of courses approved for credit toward the AB 487 requirement. The continuing education website for state medical schools for approved courses was also examined. In addition, the authors included a convenience sample of courses offered by private vendors in their examination of course curricula, looked for indications that objectives or content included racial or ethnic factors of health disparities, and reported the outcome.

6. Conducted narrative interviews with selected key informants, identified experts, and other stakeholders; and

Preliminary findings were presented to selected key informants, identified experts, and other stakeholders in informal discussions. Their insights were incorporated into comments and recommendations in this report.

7. Incorporated co-authors' previous scholarship and work in this area.

Drs. LaVera Crawley and Marjorie Kagawa Singer are recognized experts in the area of cultural diversity and care at the end of life. This report reflects insights and previous scholarship they have contributed to the field.

Appendix A. How Top Ten Leading Causes of Death Differ among Subgroups

	HISPANIC/ LATINO	MEXICAN/ MEXICAN-AMERICAN	PUERTO RICAN	CUBAN	CENTRAL/ SOUTH-AMERICAN	OTHER HISPANIC/LATINO (BORN IN U.S.)	OTHER HISPANIC/LATINO (BORN OUTSIDE U.S.)
1	Heart Disease	Heart Disease	Heart Disease	Heart Disease	Cancer	Heart Disease	Heart Disease
2	Cancer	Cancer	Cancer	Cancer	Heart Disease	Cancer	Cancer
3	Trauma/other external	Trauma/other external	Trauma/other external	Cerebrovascular Disease	Trauma/other external	Trauma/other external	Cerebrovascular Disease
4	Cerebrovascular Disease	Cerebrovascular Disease	Cerebrovascular Disease	Trauma/other external	Cerebrovascular Disease	Cerebrovascular Disease	Trauma/ other external
5	Diabetes	Diabetes	Diabetesw	Chronic Respiratory Disease	Diabetes	Chronic Respiratory Disease	Chronic Respiratory Disease
6	Cirrhosis/ liver disease	Cirrhosis/ liver disease	Alzheimer's/other nervous system disease	Diabetes	Cirrhosis/ liver disease	Diabetes	Alzheimer's/other nervous system disease
7	Chronic Respiratory Disease	Chronic Respiratory Disease	Chronic Respiratory Disease	Alzheimer's/other nervous system disease	Alzheimer's/other nervous system disease	Alzheimer's/other nervous system disease	Dementia/organic mental disorders
8	Alzheimer's/other nervous system disease	Alzheimer's/other nervous system disease	Cirrhosis/ liver disease	Nephritis	Chronic Respiratory Disease	Cirrhosis/ liver disease	Diabetes
9	Perinatal	Perinatal	HIV/AIDS	Dementia/organic mental disorders	HIV/AIDS	Dementia/organic mental disorders	Nephritis
10	Nephritis	Nephritis	Dementia/organic mental disorders	Cirrhosis/ liver disease	Nephritis	GI System Disease	Cirrhosis/ liver disease

	ASIAN AMERICAN	CHINESE	JAPANESE	KOREAN	VIETNAMESE	CAMBODIAN	THAI	LAOTIAN	HMONG	FILIPINO
1	Cancer	Cancer	Heart Disease	Cancer	Cancer	Cancer	Cancer	Cancer	Heart Disease	Heart Disease
2	Heart Disease	Heart Disease	Cancer	Heart Disease	Heart Disease	Heart Disease	Heart Disease	Heart Disease	Cancer	Cancer
3	Cerebrov. Disease	Cerebrov. Disease	Cerebrov. Disease	Trauma/ External	Cerebrov. Disease	Trauma/ External	Trauma/ External	Cerebrov. Disease	Trauma/ External	Cerebrov. Disease
4	Trauma/ External	Chronic Respiratory	Chronic Respiratory	Cerebrov. Disease	Trauma/ External	Cirrhosis/ Liver	Cerebrov. Disease	Trauma/ External	Cerebrov. Disease	Trauma/ External
5	Chronic Respiratory	Trauma/ External	Trauma/ External	Chronic Respiratory	Chronic Respiratory	Diabetes	Alzheimer's	Chronic Respiratory	Chronic Respiratory	Chronic Respiratory
6	Diabetes	Diabetes	Alzheimer's	Diabetes	Alzheimer's	Nephritis	GI System Disease	Nephritis	Diabetes	Diabetes
7	Alzheimer's	Alzheimer's	Diabetes	Alzheimer's	Diabetes	Chronic Respiratory	Chronic Respiratory	Infectious Disease	Nephritis	Alzheimer's
8	Nephritis	Nephritis	Dementia	Nephritis	Infectious Disease	Alzheimer's	Diabetes	Cirrhosis/ Liver	Alzheimer's	Nephritis
9	Infectious Disease	Infectious Disease	Nephritis	Infectious Disease	Cirrhosis/ Liver	Infectious Disease	Cirrhosis/ Liver	GI System Disease	Cirrhosis/ Liver	GI System Disease
10	GI System Disease	GI System Disease	Infectious Disease	Cirrhosis/ Liver	Nephritis	HIV/AIDS	HIV/AIDS	Perinatal	Infectious Disease	Infectious Disease

Appendix B. Fresno Pharmacy Survey

Stanford University Center for Biomedical Ethics and University of California, Berkeley School of Public Health

Access to Pain Medication in Neighborhood Pharmacies

DATA COLLECTION QUESTIONNAIRE

Pharmacy Demographics

1. Chain / Independent
2. How would you define the racial/ethnic composition of the population you serve?
3. How broad is the geographic area you serve? i.e., Are most of your customers local (within a few block radius of the pharmacy)?

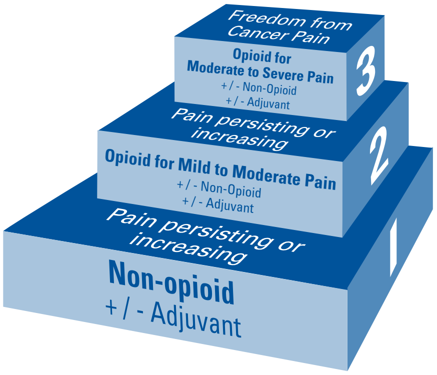
Inventory

1. How often do you place orders?
2. What do you do with unsold medications? (Transfer to other pharmacies or absorb cost)
3. What is your margin of over-the-counter medications vs. prescription medications?

Supply of Pain Medication

1. How do you make decisions about the volume of medications you stock at each level of the Pain Relief Ladder?
2. If a customer comes to your pharmacy with a prescription for a pain medication you do not have in stock, what do you do? Do you send them to another source?
3. What over-the-counter pain medications used at the bottom on the Pain Relief Ladder are available at your pharmacy?
4. Now consider the pain medications used in the second and third levels of the Pain Relief Ladder. Each is listed below. Please indicate whether or not you currently have them in stock. If you do have a medication in stock, please write in the dose(s) that is/are available at your pharmacy. If you do not carry a certain medication, please state the reason(s) why not.

WHO's Pain Relief Ladder



OPIOID CATEGORY	IN STOCK*	DOSE (mg)
I. Long-acting		
Fentanyl Transdermal Patch	Y / N	________
Controlled Release Morphine	Y / N	________
Controlled Release Oxycodone	Y / N	________
Methadone	Y / N	________
Levorphanol	Y / N	________
II. Short-acting		
Immediate Release Morphine	Y / N	________
Hydromorphone	Y / N	________
Immediate Release Oxycodone	Y / N	________
Butorphanol	Y / N	________
Meperidine	Y / N	________

OPIOID CATEGORY	IN STOCK*	DOSE (mg)
III. Combination Products		
Acetaminophen and Codeine	Y / N	________
Acetaminophen and Oxycodone	Y / N	________
Aspirin, Oxycodone, and Oxycodone Terephthalate	Y / N	________
Proxyphene	Y / N	________

*Yes or no—if “no,” why not?

Appendix C: Focus Group Report

Stanford University Center for Biomedical Ethics and Lake Research Partners

Providers Discuss End-of-Life Care for California's Minorities

A REPORT FROM TWO FOCUS GROUPS

January 5, 2005

Introduction

In November of 2005, Lake Research Partners (LRP)—working with and for LaVera Crawley, MD, MPH and Marjorie Kagawa-Singer PhD, RN, MN—conducted two focus groups with health care providers who provide end-of-life care for minority patients in California. These groups were part of the research for the report *The State of Knowledge of the Impact of Racial, Cultural, and Ethnic Factors on Quality of End-of-Life Care in California* [working title] being funded by the California HealthCare Foundation. This report will provide an in-depth summary of the state of end-of-life care for California's multi-ethnic, multi-cultural, and racially diverse population, identifying progress that has been made as well as gaps that remain. The report will focus on four core issues: decision-making at end-of-life; pain and symptom management; support for family and caregivers; and communication.

LRP conducted focus groups in Los Angeles and Fresno with a diverse group of end-of-life health care professionals. The groups included nurses, home health care aids, social workers, chaplains, volunteer coordinators, and administrators working in both hospital and hospice settings. We did not include doctors in the focus groups. This report reflects the first level of analysis of the focus group transcripts. In a later stage, these results will be combined with the results of the semi-structured narrative discussions and analyzed using iterative grounded theory methods.

It is important to note that these findings are based on only two groups. Moreover, the moderators guide was revised after the first group so that some issues were discussed differently and some new issues were discussed in the second group. Note, too, that our insights are based on participants' direct comments as well as our interpretations and extrapolations of their comments.

This report begins with five case studies that participants discussed or wrote about in the groups; these case studies provide some context and a picture of how racial, ethnic and cultural factors impact quality of end-of-life care. The second section explores what participants said—and did not say—about how these factors influence their work. The third section discusses the different cultural norms that affect end-of-life issues with various minority communities. The next section explores what was learned about trust and strategies for building trust. Section five talks about advance directives, and section six is about pain management. The final section contains further insights and barriers to quality end-of-life care.

Case Studies

This section looks at five cases involving minority patients and end-of-life issues. These case studies provide an introduction to and context for the remainder of the report. Toward the start of each group, participants were asked to write a brief piece on a recent case involving a minority EOL patient.[1] The case studies shown below are mostly those explored in this exercise.

Case Study One: An African-American Family has Concerns about Care Being Withheld

The participant, and ICU nurse in Fresno wrote the following:

> "Young 21-year-old male (African-American) with metastasis lung cancer in the ICU made a DNR per family spokesperson who was [his] brother. Family did not want to withdraw care, when pt eventually died, multiple family members angry, upset, screaming, jumping on bed to perform CPR and stated if we had insurance or were white you would do something instead of standing there. Complete transition from attitudes and discussions prior to

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[1] See Handout One in the final moderator guides (both versions). Note that participants were instructed not to discuss the case in any way that would breach confidentiality.

> death, appeared obvious mistrust and understanding by majority of family."

The participant further explained that the family's reaction was particularly surprising because, "[there had been] a lot of discussion about end of life care, and what it was going to look like," and that these discussions, which eventually led to the decision to keep him on the respirator (not withdraw care) and to the signing of a DNR, had gone "really well." According to the participant, there had been no hint of the issues that arose when he did die, which included accusations that the hospital staff had "let him die because of monetary issues, and that if he was Caucasian, or that if he had insurance that we would have continued treating him, etc. etc." She explained, "[There was a] lot of anger, a lot of angry family members, but it was the mistrust, and what it turned out to be probably miscommunication with other family members, and stuff…It was a very just difficult situation and the mistrust…"

In discussing why she had chosen to write about this case she explained, "it was just a very different take on maybe looking at end of life care in a certain population, looking at socio-economic as well as ethnic minorities."

Case Study Two: A Large Number of Visitors for a Latino Patient Causes Conflict

A hospice volunteer coordinator from Fresno wrote the following:

> "At our inpatient facility, a young Hispanic male had over 70 visitors one evening. The facility is located in a residential area. The number of vehicles, music, voices and sheer chaos led our administrator to call in our Spanish speaking staff to explain the necessity of keeping the number of visitors and time of stay to less than the current experience. Even though this was handled diplomatically there were hard feelings between friends, family and organization."

The participant explained that the patient was "an incarcerated young male compassionately let out," and since no family members could care for him he was placed in their in-patient facility. She explained,

> "One evening there was over seventy visitors, and the home is in a residential area kind of, and the people there are kind of snobby. We always have problems with them calling the mayor and stuff, so we're always careful about how many cars are on the street. Well, with 70 people, and probably 35 cars in a very small residential area, and then everybody had a music box, and everybody was talking, and they were excited to see their friend."

The participant went on to explain that they had to "call [their] Spanish speaking staff to come and explain about the residential area, and not having the only six bed in-patient facility in the whole San Joaquin Valley close down because of the noise." She noted that, "even though it was done very diplomatically there were feelings hurt." She concluded, "So it was just the way we saw it versus the way they were seeing it, which is very common for them to gather in the front yard."

> *We bend over backwards, like [another participant from the same organization] said to do the burning of the incense and whatever the family wants, even though it was done very diplomatically there were feelings hurt—like we were being too tough on what was actually happening.*
>
> —Volunteer Coordinator, Fresno

Case Study Three: A Hmong Family Believes Health Care Provider's Actions Precipitated Loved-one's Death

The participant, a Hmong mental health clinician from Fresno, told the group about the following case,

> "The one that I wrote about was Hmong. That was very much mistrust. An elderly gentleman that came in for surgery, a fairly normal bowel surgery, he had a blockage, and it shouldn't have been a lot of complication. He developed complications. The family felt that we got him up too soon after the surgery, and that was the reason why he was having complications. That whole mistrust went through a period of several weeks, because he ended up in the intensive care unit on a respirator. To get past [the family's feeling that we] got him up too soon was very difficult.

The participant added that identifying the "contact person is that you can talk to"—a critical step with the Hmong population—was also "very difficult." He explained,

> "[There was] a son, a fairly young son that was very good at speaking English, fairly knowledgeable, but he could not really make [decisions], because he had

> to bring in the brother of the patient, his uncle. And his uncle was there, and we had to make sure that he was there when we had our conferences with the doctor."

Case Study Four: Chinese Daughter Not Wanting Her Father to Know He Is Dying

The participant, a palliative care nurse who works on transitioning patients to hospice care shared the following story:

> "I was thinking about a Chinese patient who had an advanced cancer and there had been an order to evaluate for hospice. In talking with the daughter, she was extremely protective of her father and felt that she did not want him to have any bad news, though he knew what was wrong with him. We had a long conversation about how we were going to do hospice in the home without him knowing that. It was very important that she felt her role was to protect him, that being a good daughter was to protect him, and so was trying to deal with that and provide him with good care."

What surprised the participant about this case was not that the daughter was reluctant to discuss death with her father, but that the daughter seemed very assimilated. As the participant explained,

> "The daughter was a very high-powered business-woman, very urban, very now, and yet there were these values from her culture that kind of took over and it was kind of a conflict. You could see it in her and that is how she struck me, because I could see both things happening at the same time. She knew this wasn't how western society would do things, but she had to do it that way."

Case Study Five: Middle Eastern Patient, Pain Management Issues

The participant, an administrator from a Los Angeles hospice, wrote about the following: "A recent case involved a young Middle Eastern male who had uncontrolled pain requiring high doses of analgesics. Due to cultural issues the patient's family refused to give the medications as directed causing undue suffering." When asked to talk about the case he said,

> "A young Middle Eastern man who had uncontrolled pain, ended up requiring medications in a dosage that I had never seen before and the pharmacies had never seen…. Due to some cultural concerns, the family refused to have the medication increased to the amount where the hospice believed the patient would be more comfortable. So the hospice believed that the patient suffered unduly and it was a challenge."

When asked about the cultural concerns he explained, "The family made it clear that in their culture, there comes a point where patients have to be, you have to be awake, aware and even if that meant compromising comfort."

When asked why he had chosen to discuss this case, the participant explained that it raised interesting ethical issues in that the patient himself wanted relief and the family was preventing it. In fact, the ethical issues were so great that they even considered discharging the patient. According to the participant, had the patient not been asking for relief, they would have been more comfortable giving the patient what they saw as inadequate pain relief. The participant explained,

> "[I]f the patient himself said, 'No I don't want it," that would be a different story, but the patient was asking for relief and the family, behind the patient's back, was refusing it. My biggest concern was not legal, but this was a man who was asking for some relief…."

The administrator explained that, while issues about the balance of pain and lucidity are not uncommon this case was unique because, "…most families, in my experience, with good education, get to the point where they understand, as long as there is good, consistent education, but it seemed like no matter the education that we gave… They wanted him to be awake at all costs, even though he wanted relief."

I picked this one because it was ethical dilemmas. There was a great education for the staff, the staff had a lot about their own expectations that could have, should have happened, and administratively, it was a good case to use for a lot of different reasons. It taught the staff a lot of different things.

— HOSPICE ADMINISTRATOR, LOS ANGELES

Participants' Feelings about the Influence of Racial, Ethnic and Cultural Factors

Many Participants Seem Ill-at-Ease Discussing This Issue

Many participants, particularly those in Los Angeles, seemed uncomfortable talking about the issues raised in the focus group; some were even defensive. This was reflected in what they said, and what they did not say. Specifically, several participants, in sharing the cases they wrote about in the initial exercise were hesitant to name the race or ethnicity of the patient they were discussing. They just said, "a minority patient" and only identified the minority when asked by the moderator. Often when they did discuss the tendencies of one group or another they qualified their statements. For example, in discussing the Filipinos, a Los Angeles participant said, "I am not bashing cultures, it is just they are notorious for the feed, feed."

It also seemed, perhaps not surprisingly, that those who were themselves members of the minority group in question spoke more bluntly, and even harshly, about their own culture. They were also more likely to generalize. Some raised issues that others did not. For example, a Latina medical social worker from Fresno explained,

> "Because I'm bi-lingual, I worked a lot in the intensive care unit with the Latinos, and some of the recurring themes in working with them were again, negating what the physician has to say, a lack of understanding and wanting conferences all the time. Conference again to hear the same thing again, and just having a real difficulty, and I'm not so sure it was about semantics, in accepting or even looking at, or even considering that, yes, the prognosis is this poor. I encountered a lot of minimization of situations, conditions, issues, a lot of that, on the negative side."

Though other participants in her focus group agreed with her statement, none made the point, or indeed any point, quite that forcefully. Similarly, a Hmong mental health clinician in the Fresno group had more to say about the specifics of working with Hmongs than some others in his focus group.

It also seems worth noting that some participants sometimes seemed more comfortable giving examples of patients and families that go against stereotypes.

> *It is a process that is so unpredictable. Even somebody that could be totally familiar with a family and all of a sudden, the patient is declining and nothing follows a pattern. It has nothing to do with culture.... It is just that is the nature of dying and how it affects people.*
>
> — SOCIAL WORKER, LOS ANGELES

While some see that the race or ethnicity of the patient, family and provider affects interactions, others are more reluctant to acknowledge this.

Some participants admitted that, at a basic level, they are more comfortable discussing end-of-life issues with people of their same culture than with others. For example, a Latina palliative care nurse from LA explained,

> "When I walk in to discuss end-of-life issues with my own culture there is just such a, for me and I hope for them also, just such a comfort level. When I go into the other cultures, I don't have that same comfort level I have within my own culture."

Most participants, however, especially at the start of the groups, said that they are able to find connections that transcend racial, ethnic and cultural differences. As a Los Angeles hospice volunteer coordinator explained, "I really, truly believe if you are going in with your heart, you are going to be very pure, you will find the bond." A Los Angeles hospice chaplain explained, "For me it is different, because I think with different patients and different families, there are different connections that get me. Regardless of culture, because the bridges can be different. You know with some, it is that whole spiritual base, with some it is Christianity, with some it is race." Others also balk, at least initially, at the idea that their work is in any way affected when they are working with a person who is not of their same group.

> *Well I think one of the problems that comes up is that everybody has their comfort zone and if I go and visit a family that is Anglo, middle-class or whatever, I could go in thinking oh I know this family because they are my comfort. Well you know, maybe they are not. It does not matter if they are Hispanic or White or Black. It doesn't matter.*
>
> — HOSPICE NURSE, LOS ANGELES

Some participants, once immersed in the conversation, had an easier time seeing that the different backgrounds of providers and patients may influence the interaction. For example, the chaplain quoted above later said in the group,

> "I think somehow, I am White, I am middle class, I do my very best when I am with any family or any culture and all of that, but I would be naïve to say that there is not bias in the care. I mean because I am part of the majority race, I am not even aware of the biases, because I am part of the majority. It is only when I get into the minority that I recognize oh yeah so there is the difference, so it is a difficult question. Again, I am going to do my very best to overcome the biases that I have coming into a situation, but I would be totally naïve if I really thought that I was 100 percent successful all the time. I am not…. I mean I think I am doing the best that I can with what I have now. That doesn't mean I am done learning and a year from now I hope to be even better because I will have encountered other people and I will have had the opportunity to listen to them to hear some of the differences, to hear it is like oh yeah, they grew up that way and then I grew up this way and so there is a little bit difference and that teaches me to be aware on a different level for the next people."

An LA administrator suggested patients and families might accept the concept of advance directives more readily if they were delivered from someone of their same background. As he put it,

> "I think the exact same message and the same reading delivered from one culture as opposed to theirs, I think would be totally interpreted differently. I think many times. I think people would get it differently if it were read to them. Even if it was read in English, but it was read by someone in their own culture, I think we'd change the roles quite a bit…. Even if the language was the exact same, I think there is a certain amount of trust when it is coming from your own culture."

A medical social worker from Fresno, in discussing cultural competency training, had an idea along similar lines. He suggested that such courses might be strengthened if the person teaching the class was of the culture in question. So, for example, a Hmong person would teach the section on Hmongs.

Most participants feel acknowledging cultural norms is important, but are cautious about stereotyping.

I really think that the more cultural education we have, the better informed we are so that we can go in and be open to different possibilities. I think the education can do that, but you know we have to be careful not to just stereotype people.

— CHAPLAIN, LOS ANGELES

In general participants say that knowing about cultural norms around end-of-life issues is important and useful in their work. In the words of a Fresno chaplain,

> "For me knowing about different cultures and religious practices, really mean that's an internal resource for me, because then it gives me a point of reference, and it allows me to say okay, I'm dealing with this particular group of people, these are maybe some of the things I may see."

A Los Angeles palliative care nurse expressed a similar sentiment: "The key is to go in with the education in mind as to what the possibilities are, but always go in and ask first and know what you are expecting so that you can ask about it to see if it really is there or not."

While participants believe knowledge about cultural norms is critical, they are also concerned that relying too much on this knowledge can be dangerous, too, because, as an LA chaplain explains, "Every person is different. Each family and person is going to have certain things in common with the culture that they come from and certain things that they differ…. Everybody doesn't fit, and buy into their own cultural stereotypes." A Fresno social worker explained,

> "I think one of the things that I've learned is that you can't always assume that because I'm working with a Hmong family that they are going to be believing this way. You don't assume because you can be in sometimes bigger trouble if you make an assumption that this is what they are going to do at the end of life, when that isn't where they're at."

An LA administrator suggested that cultural training, if taken too far, can do more harm than good. He explained,

> "I think the whole idea of spending a lot of time with cultural differences may be a barrier in itself. Again,

> sort of staff maybe, okay this patient is going to do this and this, this culture does this, and so the nurse or whatever may go in and sort of [inaudible] instead of leaving everything at the door. So sometimes I think cultural diversity education, too much could be an issue, a barrier in itself."

He notes that he sees this happen with his own staff; they will make assumptions based on a new patient's last name. A hospice volunteer coordinator gave another example of such prejudgments, noting that her staff goes into a situation with Hmongs assuming that they will not talk about funeral arrangements.

The biggest barrier [to quality end-of-life care for minorities] is being seen as a stereotype of a particular minority rather than as an individual or a unique family unit.

— NURSE CASE MANAGER, LOS ANGELES

Most feel the best course of action is to go in armed with information, but wait to take the clue from the patient and his or her family.

Participants talk about going in armed with information about what issues might arise given the patient's background, but letting the patient and the family do the talking. As an LA social worker said, "I meet the family where they are. It doesn't matter what they are. I find that works." A Fresno social worker explained it this way,

> "I think going in and having them explain what is going on as opposed to that you've got to say something. Sometimes the less you say the better. Simply kind of say what is going on, and let them talk, because in that process you kind of hear and you can pick up, well I need to be very sensitive to this, but you only hear that — they have to talk, so I think sometimes you need to be able to keep ones mouth shut"

Another Fresno social worker referred to this as, "basic social work principals—go to where the client is and let them tell their story."

I listen to the words that the family and patient are using and then use those same words.

— CHAPLAIN, LOS ANGELES

Some participants—especially those from hospice—talk about this approach in terms of going in without an agenda beyond advocating for the patient and family. For example, a hospice volunteer coordinator said,

> "You know, it is their choice, and it is their culture, and it is what they want. My job is to advocate for what they want and to help see that that happens. Even if it is not possible to continue, or to get better from what is going on, but that is my job and I mean I think it is standard. We are very well trained to serve the family and the patient at all costs, no agenda, and when I train volunteers, I drill that one over and over. You walk in without an agenda."

Others put this in terms of "leaving everything at the door."

Lastly, some participants use the approach of asking for guidance. A Fresno chaplain explained it this way: "I think it is important for me when I go into a situation I encounter people that I'm not familiar with to go in with a sense of humility, and say who I am [and say], 'I'm a little lost here, can somebody help me?'" Some even use the approach of finding someone in the family to act as their guide of sorts. For example, a Fresno social worker said,

> "[The best thing is] actually finding that one person in any family to ask to teach you about their culture. That is where I've learned by far the most about anything, and then just choosing to do that every time just because you say I learn something different every time. It's like they don't use the same dress, and they are willing if you ask even through an interpreter. It's like, 'I don't know, tell me what it is for you', and then learning each time, and not making that assumption."

Similarly, a Fresno ICU nurse said training had taught her that, "you don't have the answers going in, and you're seeking them in that designated person. They will help you and or actually do the plan of care for you."

Most feel that training and classes have been helpful, as has been their on the job training.

All the participants in the focus group said they have had some training in cultural competency issues. For some it was part of earning their degree and for others it was training or workshops through their job. Most have positive comments about the training they received. A Fresno social worker said,

> "You asked how cultural competency training has helped us do our work. For me it's really reinforced the advocacy efforts for the patients. Often times I've gone to a training and been presented with various rituals, beliefs, faiths, and it's more having the knowledge that it is important to them. Sometimes I don't understand, and they'll ask me, you know when I talk to them, about what's concerning them, or whatever and they'll tell me, well this is what we need to do. It's really reinforced the advocacy efforts. We need to advocate because to them it's important. To them it's going to make a difference. To us it may not mean anything, but to them, you're making a difference to them, and that should mean something to us."

A Fresno ICU nurse said, "[I had some] training in the last year and I think the one thing that it did do for me is it gives you the sensitivity to get outside your own box, and just to walk in with an open mind, and serve the patient with a sensitivity,"

At least one participant, however, raised some doubts about the accuracy of the training she received. This participant, a Fresno hospice nurse said, "They did a cultural deal, and when they came to the Mexican American, I thought you know I'm Mexican American, and that doesn't sound like me, or my family, or my cousins, or my uncles, so I don't know where you got your information, but you're totally wrong." This participant explained that since the training misrepresented her culture she was doubtful about the accuracy of what she was taught about other groups.

Participants also believe that on the job training and experience is invaluable. Several suggested that it is even more valuable then any classroom training or education they have had.

Racial, Ethnic and Cultural Factors; Norms and Stereotypes

Most participants seemed reluctant to talk about cultural norms, perhaps for fear of reinforcing stereotypes or presenting groups as homogeneous. Nevertheless, over the course of the focus group discussions they did share some thoughts on the tendencies of different groups. Sometimes they did this in reaction to direct questions and other times in response to less direct inquiries.

> *I think with some cultures, there is also a fear that they are not going to get—that we are going to be taking things away from them rather than giving them things. I think in some cultures, there is a feeling that they have already felt persecuted because of what has happened to them in our society.*
>
> —PALLIATIVE CARE NURSE, LOS ANGELES

Concerns about Care Being Withheld

Participants said that some groups, African Americans in particular, are difficult to talk with about withholding treatment. DNRs are moving to comfort care. A Fresno social worker explained,

> "[W]orking in the intensive care unit where that question in regards to the extent of treatment, making decisions regarding DNR, to approach a black family with that question there is always like this well you're not going to provide care. Always you can just feel that, that anytime you ask that questions it's like well, you're just not going to take care of him, because that's why you want to get the DNR. It's a real struggle to try to define, say we're continuing care it is if something additional happens, as far as do we extraordinary measures or aggressive measures, but that mistrust is so strong."

Case Study A is also an example of this.

Some participants point out that it is not just African Americans, but also other minorities who are suspicious of health care providers' motives when they suggest signing DNRs or forgoing curative care. A social worker in Fresno said Latinos' suspicions are often aroused when the family is approached by the donor network. She explains, "Many, many families have confirmed how much mistrust there is in the Latino culture when it comes to where the donor network gets involved and they'll make comments such as I knew it, I knew it, this is why, and no, I don't want to talk about it."

Participants also pointed out that some cultures—especially Filipinos and Armenians—are especially reluctant to withhold any care. A hospice volunteer coordinator from Los Angeles said,

> "The Filipinos, by and large, want everything done. You have a 92-year-old who has heart failure, emphysema and dementia and he is saying I want everything done, I want to be a full code, and I want to have my heart restarted. The family is saying no we are not going to sign anything you have to keep treating."

Some of them have to go from A to Z because that is the culture. So I have stopped spinning my wheels when it comes to certain cultures.

—PALLIATIVE CARE NURSE, LOS ANGELES

A Los Angeles hospice nurse said, "We have a lot of Armenian referrals, and we joke about it. Why are they even referring them? They will not comply with anything." A palliative care nurse from LA made a similar remark: "Well again, the Armenian families almost always will not sign a DNR or if they do, they change their mind, and they call 911, and they tear it up."

Reluctance to Talk about or Plan for a Loved-one's Death

I also find that the people who are African American many times don't talk about "death" directly. You can talk about "passing on".

—CHAPLAIN, LOS ANGELES

Participants say that they find patients and families from some groups—especially African Americans, Latinos, and "some Asian cultures"—are especially reluctant to talk about a loved-one's death. Case Study Four is one example of this tendency with Chinese patients. Along similar lines an LA chaplain said,

> "One of the things that really does come up, I think, especially like with Asian cultures, is that it is kind of understood by a culture that when a person is dying, we don't talk about it. We don't talk about it, and the family doesn't talk about it. It is not so much a denial as it seems to be kind of a holding place, and the patient instinctively knows that they are dying, I mean all the signs are around them. One of the problems I think that comes up is when they come up against American culture with this sort of you tell it like it is. They are kind of caught off guard and there can be some unnecessary conflicts if those things aren't understood."

Participants also note that issues about end of life—and serious, personal topics in general such as a patients' conditions or wishes—need to be approached slowly and "built up to" over several visits with some cultures, especially Asians.

Participants talked about two related reasons that seem to underlie patients', and to an even greater extent families', reluctance to acknowledge death. First is the idea that by mentioning death you will make it come. As a Fresno social worker explained, "You know working with Latinos it's like don't talk about death because it will come." In her initial exercise, an LA social worker wrote about the daughter of an African-American patient who would not accept her mother's terminal diagnosis and would not let the providers share it with the patient. This despite the fact that, according to the participant, the patient was "very much aware that she way dying." According to the participant,

> "[The daughter] believed that the patient would be healed through her belief in God and the daughter stressed that I don't mention it because the patient will survive if I don't mention it. If I mention a word about her diagnosis, then that may kill her."

As the quote above suggests, there is also some religious underpinning to people's reluctance to acknowledge that a loved-one is dying. As a Fresno participant explained, "There is that faith being that one day they will get out of it, and you know what they would be very mad if I didn't give them that chance." An LA social worker said, "I think when you are dealing with a family that has a very strong religious background, you are going to have people praying and believing that God is going to heal right up until the end."

On a similar topic, a few participants note that Latino patients are reluctant to make their wishes known to their families and may leave decisions up to the family.

A Fresno home hospice nurse, in her initial exercise wrote about, "An elderly Hispanic male that chose not to pursue active treatment for early stage cancer. He had eight children, who he deferred all decisions to, he did not want to be told anything, especially that when the end stage arrived." Similarly, a Fresno social worker explained, "There is almost this intrinsic trust that when that time comes, your family will know what to do. So it is not a worry, it is not a concern so why are you stressing it?" As the section on advance directives discusses, this may be one reason advance directives are not always an effective tool for this community.

This reluctance to talk about or plan for death is further discussed in the section on advance directives.

Acknowledging the Extended Family, Respecting Family Hierarchies and Identifying the Correct Contact Person and Head of Family

> *Age can be very important with Native Americans. I was thinking about the one I wrote about, which was I mentioned about Native Americans, and I knew enough, even though the parents were there of this young man, when I went to meet this family I didn't go to the parents. The very first person I went to was the oldest person in that room who turned out to be his grandmother, but that was important, because I acknowledged that she was the matriarch of this clan.*
>
> —CHAPLAIN, FRESNO

Participants mentioned two aspects of Hmong and Native American culture, and to a lesser extent Latino culture, that providers must recognize this in dealing with patients and families. First is that the patients' extended family (or clan in the case of the Hmongs) will be involved and present, as opposed to just their immediate family. In the case of Hmongs, some participants note that the clan will be "consistently present." A Fresno social worker explained, "They wanted to be at the bedside twenty-four seven and that would create challenges with the nursing staff who would say, no, you need to leave, and they would plead to please let me stay."

The second aspect is the importance of identifying and deferring to the correct person. As a Hmong Fresno mental health clinician said about working with his own culture, "In the Hmong culture we tend to value the elderly, so I am a young person, so whatever I say sometimes they don't weigh my information a lot. Sometimes I also ask a clan leader to clarify something on behalf of me." In fact, in Hmong culture it is the extended family and clan leaders, not the patients, who make decisions according to a few Fresno participants. Similarly, a Fresno participant said about Latino families, "You need to know all the players….[D]etermining who that decision maker is, or who you need to have contact with, especially when you have a large family in the Latino community, identifying who that is [is important]."

According to participants, in the patriarchal Hmong culture the contact will generally be the eldest male, and among Native Americans it will likely be the eldest person present. In Latino families this is less clear, though it is often one of the patient's children.

> *With different cultures there can be an element that it is important for people to come and see the person before they pass away. So the Hmong, the Latino, the Spanish, Black, I think that is very important that they be able to come, and see the person before death, and that's a little bit about how do you control the number of people in a hospital.*
>
> —SOCIAL WORKER, FRESNO

Participants mentioned various other cultural traits, including:

- The Hmong practice of coining is often misinterpreted as a sign of abuse. A Fresno palliative care nurse recalled, "That was an eye opening experience when I walked into the room to see the younger man coining his grandmother."
- One participant wrote about the case of a Hmong woman with cervical cancer but refused treatment because, "believed if a part of her body was removed her spirit/soul could not be reborn." The mental health clinician who wrote about this case, himself a Hmong, said that she refused treatment despite entreaties from her clan relatives and shamans. Some LA participants mentioned similar concerns about the wholeness of the body among orthodox Jews.
- This same Hmong mental health clinician said that, because Hmong culture is rich in oral tradition they

often answer simple questions with long, involved answers. As the participant said, "Sometimes the clinician would say, 'I just asked one question, how come you give me all kinds of answers I don't understand it.'"

- According to participants, Hmongs, Filipinos, and some other cultures show respect to elders by feeding them, an issue that can come into play at end of life.
- The Latina social worker quoted on page six, said that people from her own culture, tend to negate diagnoses and require multiple conferences with providers in which the same topics are covered repeatedly.
- A few participants mentioned that some of these cultural tendencies are less pronounced among younger, more assimilated, members of a particular culture. An LA hospice volunteer coordinator noted that you could have a third generation Korean who, if treated in a traditional way, might say, "I am American, you know, I may look this way, I am like you, so stop treating me this way."

Please note that some other norms are discussed in other sections.

Trust and Strategies for Building Trust

Most Participants Believe Trust—or Lack thereof—is a Major Issue in Dealing with Minorities around End-of-Life Care

> *In regards to the trust, I think one of the things that is very prevalent is the socio-economic level, if they don't have insurance… [Family members ask,] "Will he get treatment or is the treatment different" and having to explain to them that the doctors don't even see, nor do they care if they have or don't have insurance. But to them it is so oppressing.*
>
> —SOCIAL WORKER, FRESNO

Participants believe that trust is critical to a successful relationship between patients, families and providers. As an LA palliative care nurse put it, "Trust is everything…. [O]therwise, you will hit a wall." Participants said they experience a lot of mistrust in their interaction around end-of-life with minority patients and families.

Many of the specifics of the trust issue have already been touched on. Specifically, participants said that Latinos and African Americans are very mistrustful of the health care system and suspect that they are treated differently than whites, especially in regards to the quality or continuation/cessation of care. (See Case Study A and Concerns about Care Being Withheld). Some participants believe that these trust issues are especially pronounced among those who are uninsured and lower-income patients and families.

> *I feel like they are going to misinterpret what we say.*
>
> —ICU NURSE, FRESNO

Our limited efforts to get participants to talk about trust from their own point of view were not very successful. Only a few participants were willing and able to talk about their own trust or mistrust of patients and families. A Fresno palliative care nurse said, "[S]ometimes you don't feel like you could trust that they will accept that you're wanting to provide the best service that you can. Sometimes the best service you can provide them is to just leave them alone." An LA hospice coordinator, talked about being particularly "careful" with some families because of fear that "they are going to write something in the family survey and they are going to do this and that."

Strategies for Building Trust

In limited discussions about building trust, participants mention the kind of process discussed above—going in with an open mind, listening and meeting clients where they are, and slowly building a relationship. When asked about strategies for building trust, a chaplain from LA said, "Probably nonjudgmental presence and listening when they finally come to that place where they realize that you are not going to jump down their throat about something. You are going to accept them just the way they are without having to change them." An LA hospice nurse stressed the importance of following up, explaining, "[if] you say that a bed will be there, it will be there. If I say I am going to call the next day about some pain, I need to really do that."

One interesting side note on this topic: An African-American social worker from LA said that when she speaks to an African-American family she just says that she is from hospice. She does not say that she is a social worker because they might think she is there to "find out something's going on at home that shouldn't be."

Advance Directives, DNRs and DNIs

Participants Say Advance Directives are Rare among Minority Patients

Many participants, when asked, say that minority patients are much less likely to have advance directives than White Californians. As an LA palliative care nurse explained,

> "Well I think there are many cultures that you just never see advance directive with, many groups, and they look at you when you ask that question, if it is going to hospice and doing it in a sense I have to ask that specific question and they will often look at you like… I ask them, this question is, do you have an advance directive? They will look at you and say well what is that? Then I will say what it is and they will say oh you mean like a will with a lawyer, sometimes things like that they will kind of think it is. Yes, heard the term and I think it is just something that is not well known in many minority communities and accepted."

Some others agree that advance directives are rare among minority communities.

Many feel this as much an issue of socio-economic status as race or ethnicity. As a Fresno social worker explained,

> "Having worked in two different hospitals… Clovis where it is primarily Caucasians and high social-economic verses UMC where it is minorities in crisis. I think I saw one advanced directive in the Latino population that I worked with, one. At UMC they are so far from it. They are not very receptive. These are people who are thinking about where am I going to sleep when I get out of here? Are you going to give me a bag lunch when I leave? They are looking at purely basic needs, so I haven't seen it in place in that."

Other participants in Fresno agreed. A hospice volunteer coordinator said, "I always see it as Maslow's hierarchy, because the upper white middle class has the time and the money to go to the lawyer and have it drawn up. Where some of the people you're dealing with are worried about how they are going to have enough money for dinner tonight for their family, because they didn't get to work today, because they were in the hospital."

When discussing the usefulness of advance directives with minority communities, participants point out that culture and language are barriers. A Fresno social worker explained,

> "Part of the problem is how the advanced directive is set up. It is basically checking a box, and how it's written out is in very legal language, which is kind of from the Caucasian culture, and so unless you want to do something more which is another step, when you write your own, when they're approached it's simply checking the box, which in how that is said is in a language, or a form that they're not used to."

Some others agree that forms can be off-putting to the uninitiated.

An LA hospice administrator expressed concerns about language saying,

> "A lot of it could be how it is written. It is usually written in English at a certain level. It would be much nicer if it were written in different languages, and at different educational levels. It is written in one standard level, and I don't think a lot is taken into consideration, educational background and reading levels, and whether it is a 6th grade, 8th grade. That is important."

Others point out that language is an issue. A Fresno social worker pointed out that even when the forms are available in Spanish they are often written at too high a level for the Latino community.

Participants Have Mixed Feelings Regarding Asking about Advance Directives, DNRs or Code Status

In limited discussion on this topic, we found that some participants find asking minority patients about advance planning and related paperwork difficult. Most say it is something that they work up to slowly. A palliative care nurse from LA said, "Building the relationship and as they learn to trust you and often the patient starts out [not willing to listen], but as you go, the relationship, when they trust you, you reintroduce it. I think it is the relationship building and as they get to know you."

An LA palliative care nurse said that bringing up the issue of advance directives and DNRs is especially difficult with new patients. She explained, "I was just going to say the hardest, when you first go admit someone and you have to know their code status, and you have no relationship, I find that the hardest. I was talking to a man the other day and he just looked at me and he said, 'But there is nothing wrong with me.'"

A Fresno participant pointed out that having to ask a patient if they have an advance directive—as is required—can be a good thing. As he explained,

> "I think on one hand that is good, because somebody that is coming in the hospital if they have been there a couple of times they know they are going to ask me again if I have an advanced directive to the point of maybe I should do something. It is repetition, and it has come through the process that that is one mechanism by which people can indicate what their wishes are. I think in the sense that has been good that there is a requirement that they have to ask for that."

Later he added,

> "I think the advanced directive, one of the benefits of it is it is a mechanism by which people can talk about end of life. And really looking at it as a mechanism, because what the advanced directive does is it identifies who can make the decision and probably that's the big thing there, but often when it comes down to the actual situation it's not actually covered. You can't spell out every situation, so what's important is who is making that decision to know what the wishes are of that person. How do they know about it is by talking about it. I think talking about end of life is hard so, the advanced directive, yes, you need to do this, but what's beneficial is that they're talking."

Some other participants also made the point that introducing the idea about end-of-life wishes and decisions by asking about DNRs or advance directives can be a useful tool. It is a chance to educate patients and families, raise awareness, and initiate and inform conversations. An LA palliative care nurse also praised the idea of bringing up the issue early and often. As she put it, "Introduce it early, that way it wouldn't be so scary."

Pain Management

Participants spent some time talking about pain management. It is worth noting that some of the issues that came up seemed to be universal and not specific to cultural minorities. Following are the issues that arose.

Pain Control is Easier to Achieve in Hospice Settings

In our somewhat limited conversations on this topic, participants said that pain control is handled better in hospice settings. As a palliative care nurse from LA explained when asked if patients get adequate pain relief, "I think it depends where you practice. With my hospice background, it was easy. In the hospital, it is the hardest thing in the world…" Others agreed that patients are more likely to get inadequate pain control in a hospital setting. An LA Hospice nurse explained,

> "I feel there is not a lot of education about proper pain management even in the acute setting and I still see nurses that think they are going to overdose people when medicines are ordered. I still see things like that and I think that affects end of life care…. I see that it is just a lack of education and how you care for someone because people do not like to talk about death."

A hospice volunteer coordinator from LA said, "Board and care facilities… are usually not well trained in hospice and they don't like it when someone [in their care goes] on hospice. People aren't supposed to die there. Usually our staff spends a lot of time working with people who work in these places to try to help them."

Doctors Can be a Barrier to Adequate Pain Relief

Participants report that some doctors, specifically non-hospice doctors, can be a barrier to adequate pain relief. As a hospice volunteer coordinator from Fresno quipped, "We know the physicians we are not going to work with. We know the physicians who think… pain is your karma." A palliative care nurse from LA said, "Some of the doctors will even say, 'You know what, if it is morphine, have the other doctors take care of it. We don't do morphine.'…Whether it is their culture, their religious beliefs, I am not sure, but if the patient needs morphine, [they'll send you to another doctor.]"

> *The doctors come from a different culture, also. They are Indian doctors or Middle Eastern doctors and they even have differences between men pain and women pain. Women pain is emotional and men pain, he is really in pain. So we have oncology nurses that are scared to lose their license if they [give patients a certain amount of pain medication].*
>
> — PALLIATIVE CARE NURSE, LOS ANGELES

The Balance Between Pain and Lucidity Present a Challenge

Participants say that in some cultures being lucid at the time of death is important, even at the cost of pain. Case Study Five is an example of this. It seems this is an issue not only about culture but about the general trade-off between comfort and consciousness. As a Fresno hospice nurse explained, "We want them comfortable, but we want them awake. You pick and choose, which do you want? Do you want them awake and in pain, or do you want them comfortable and sleeping? You can't meet those expectations sometimes, because you're not going to get it."

Some Patients and Families Have Concerns about Morphine

Some participants report that some patients and families, especially African Americans and Latinos, are concerned about taking morphine or other painkillers because of a fear of addiction. In discussing whether pain and pain control issues need to be approached differently with patients and families of different cultures a Fresno hospice nurse said, "You've got some that will say there are going to be addicted to morphine. Well, come on they are already dying."

A few also suggest that this reluctance to take morphine stems from a concern that it will hasten the patient's death. A Los Angeles participant said, "There is fear with some of the patients of taking morphine and fear on the part of the families that when they give the patient the morphine that it will be the dose that kills them. That is something that we have to address with education."

Some Participants Stress that Recognizing that Pain is Multi-Faceted is Key

Some participants, especially those in hospice, feel strongly that all different kinds of pain must be recognized and dealt with. As a Fresno hospice nurse explained, "Sometimes you have to treat the emotional pain, the psychological pain, and then the physical pain so you are going to be using multiple drugs…You have to deal with the whole person, body, mind, and spirit. And the family is also a component of their well-being."

> *[In hospice we address] not just physical pain but also spiritual pain [and] emotional pain.*
>
> — CHAPLAIN, LOS ANGELES

Further Insights and Barriers to Quality EOL Care for Minorities

At the close of the group, participants were asked to write what they see as the biggest barriers and obstacles to minority patients in California getting the best possible end-of-life care. Their answer to that question, along with other comments made throughout the group, suggest that there are many barriers. These barriers are discussed in this section. Note that some of these have been mentioned above and so are just touched on; others are new. It is also worth noting that some of these barriers are universal, though they may affect minorities more significantly. This section also includes some additional insights from the focus groups.

Money, Time and Other Resource Issues

> *Resources are the greatest barriers. Money, time and people hours need to be devoted to EOL issues earlier.*
>
> — CHAPLAIN, LOS ANGELES

Many participants wrote, and spoke, about resources issues. A Fresno social worker wrote, "Greatest barrier is that health care is so much based on making money." Some participants also mention the special problems facing lower-income families and those who are uninsured or underinsured. To illustrate the point a Fresno hospice nurse told the following story:

> "For me I have mistrust of the medical field myself. I can think of two right off the top of my head a Hispanic and a Black female that they played musical, you know they passed her around, so that a 37 year old black female died because she was Medi-Cal and nobody wanted to take responsibility to pay for it, so I'm trying to advocate for the patient, and none of the doctors would play, so to speak, or the hospitals. …. It came down to money…. All she needed was a valve replacement in her heart, 37, and nobody wanted to pay for it."

Similarly, a few spoke or wrote about limited hospice benefit available through both Medicare and private insurance. A hospice administrator from LA said, "Some insurance companies have a very limited benefit …. So talking to families and they say, 'Well what about this' and [you have to say,] 'Sorry, your insurance doesn't cover it." [This can] be very difficult, very uncomfortable."

As is noted in the section on advance directives, participants say patients and families from lower socio-economic groups are not as likely to have advance directives and are somewhat less likely to have talked about end-of-life wishes with their loved-ones. Some say this is because these people have more immediate concerns.

Time is another resource participants say is in short supply. Several say that not enough time is spent with patients and families. The Fresno social worked quoted above also wrote, "Due to [the focus on money] time becomes so important. [There is a] lack of time spent with patient and families as they face end of life."

Education and Awareness

Some participants believe that raising awareness about a range of end-of-life issues is critical. As noted above in various places many feel that not enough time is spent educating and preparing patients and families about end-of-life issues and decisions. A Fresno medical social worker wrote that the biggest barriers are "Education about the end-of-life process, including physiological, social, and psychological changes, process for the individual approaching end of life. Education for the families of patients." An LA participant said, "I think there is such a fear about dying and there is such a negative association with the word hospice and I think that is a hindrance to getting the end-of-life care…"

Some also said providers (those outside of hospice) need more education about these issues. However, there is some suggestion that this is getting better. An LA hospice volunteer said,

> "There is a huge educational process going on with doctors now. I mean I worked once as a chaplain at a hospital, palliative care, and I was told, you will be fired if you talk about dying with these families. And I am like, what am I supposed to talk about? They are like don't say the word death or you are out, because they were still trying to convince other doctors and hospitals that this was okay and it was like why, because I came from hospice."

Language and Culture

Almost half of the participants included language barriers in the written response to the question about barriers. In the group discussion too, many talked about language barriers and having to use interpreters that are less than ideal. Participants say they sometimes have to use family members, which they know is not recommended or the ATandT Language Line, which can also be problematic. A Fresno ICU nurse, who has experience with both these options said,

> "We mostly had problems with family interpreting and obviously we don't know what they're interpreting, and actually having another person be there you find out they're only interpreting half of what you're telling them. So now we tend to use the ATandT line, which is very impersonal, but now we're finding problems with that just because it's an impersonal way of communicating, but there isn't another way to do that."

This same participant, in her final exercise wrote, "[The biggest barriers are] [l]anguage, especially Spanish that I have to use the interpreter which is not the same same as speaking their language." Participants also talk about having to use "staff members—anyone who speaks the language," who are often busy.

[The biggest barriers are] cultural and linguistic barriers, limited number of professionals who are from different cultural groups, [and] minorities' cultural beliefs.

— MENTAL HEALTH CLINICIAN, FRESNO

Another participant, a Fresno social worker, made the following point about language barriers:

> "I think another thing is the language. I think it is both in the Hmong, and also in the Latino, sometimes the assumption is made that they understand, because they're talking. They seem to be understanding what is being said when really they are not. I think probably in the Hmong, especially with the older persons, sometimes they have picked up enough English so you think, oh yeah, they understand what you're saying when there is not that understanding."

As touched on above, some participants also note that materials are not always available in languages and, when they are, are not written at an appropriate level.

Although some are reluctant to talk about cultural barriers and feel that they work hard to overcome them, participants (some more than others) do recognize that cultural difference still prevents minorities from getting the best possible end-of-life care.

Racism, Discrimination, and Stereotyping

In their written responses, and in some spoken comments, participants suggest that racism and discrimination are still problems. A Fresno social worker wrote, "I believe that we would need an entire mind shift change in order for the best to occur, despite our multicultural society we still have racism, prejudice and discrimination."

> *I think that it is important to know that there still is stereotyping in the medical community.*
>
> — HOSPICE ADMINISTRATOR, LOS ANGELES

Doctors

In limited discussions, some of these non-physician providers talked about ways in which doctors can stand in the way of minority patients (and Californians in general) from getting the best possible end-of-life care. As noted above, participants say some doctors are reluctant to provide patients with adequate pain relief. Some also say that doctors can confuse or upset patients and families either by not informing patients that a diagnosis is terminal, or by doing so too bluntly. This situation is aggravated when end-of-life care providers, who are supposed to help patients and families make decisions, are not told what the doctor(s) have or have not told the patient and family. Another concern participants raised is that doctors wait too long to refer patients to hospice. As a LA hospice chaplain wrote, "[One of the biggest barriers] is doctors not referring early enough."

> *A lot of things that I hear when we see patients in home health, the doctor didn't tell me anything, we don't know anything, we can't get a hold of the doctor, we call and call and call, so the information is like there is a huge information gap.*
>
> — HOSPICE NURSE, FRESNO

Setting Makes a Difference

The focus group findings suggest that setting makes a difference. End-of-life care in hospice, and to a somewhat lesser extent in palliative care units, is better than care in ICUs and elsewhere in hospitals. As the previous section noted, participants say pain control is far better in a hospice setting. Moreover, most seem to exclude hospice doctors from their complaints about doctors on issues of pain control and communication with patients and families about the patient's condition.

Patients in Poor Areas Face Extra Obstacles

A few participants mentioned ways in which patients in lower-income areas face extra hurdles in getting quality end-of-life care. In Los Angeles, a few participants noted that some pharmacies in high-crime neighborhoods do not stock certain painkillers. A Fresno Hospice nurse told the following story about a patient being rejected from hospice because of the neighborhood where she lived:

> "They refused to take the patient to hospice, because due to what they perceived was that she lived in a bad end of town in a motel, and that the patient was, what they thought was smoking marijuana. Of course, she had inadequate pain control, and they felt that the situation would present, for them, an environment that wasn't safe."

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