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

Findings and Recommendations

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by

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About the Foundation

The **California HealthCare Foundation,** based in Oakland, is an independent philanthropy committed to improving California's health care delivery and financing systems. Formed in 1996, our goal is to ensure that all Californians have access to affordable, quality health care. For more information about CHCF, visit us online at www.chcf.org.

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I. Executive Summary

Efforts to improve EOL care for diverse population groups will likely result in a care system that will benefit all of California's residents.

Approximately 235,000 Californians died in 2004—a number that will increase annually as the state's population continues to grow and the demographic shift brings an unprecedented number of elderly to its census. The most populous state in the country, California is also the most diverse ethnically, and thus is in a position to provide leadership for the rest of the nation on how best to provide quality care to a diverse multicultural population.

With this in mind, the California HealthCare Foundation has focused resources on examining end-of-life (EOL) care delivery for Californians. To understand the effect of racial, ethnic, and cultural factors on the delivery of EOL care, the authors explored a range of issues critical for evaluating how Californians experience dying. They also investigated several areas in depth to report on both the progress made and the persistent gaps in delivering quality care at the end of life for California's multi-ethnic, multicultural, and racially diverse population.

Much of this report is pertinent to immigrant patients, families, and communities as it relates to culturally mediated EOL issues for persons whose beliefs, values, preferences, behaviors, and language needs differ from Euro-Americans (non-Latino Whites). However, this report also addresses issues specific to non-U.S. citizenship. For the immigrant and his or her family, accessing quality care and finding funds for hospice, palliative care, and other EOL health services is a complex and potentially confusing process that is compounded by changing laws and regulations and a polarized national climate.

This report also highlights how the patterns of dying and EOL care needs differ between immigrants and the general U.S. population and how immigration affects the workforce that provides caregiving for those who are dying.

Population-Based Approach to EOL Care

Foremost, this report follows from a critical population-based perspective that has explored and identified causes and patterns of death. Dying is a process, and death is its outcome. By first studying those who have died, from which conditions, in what kinds of patterns, and where those deaths took place, researchers may be better able to assess the care needs of those engaged in the process of dying. In addition, this approach enables them to identify future needs for different populations and indicate which groups might be at future risk for poor quality care.

A population approach to exploring the state of quality care at the end of life provides a clear comparative picture among the state's ethnic populations of who died, and how. Differential rates of death exist among the populations residing in California. Data from the Center for Health Statistics show that African and Native Americans have the highest death rates, while Asian Americans have the lowest rate of all population groups.

Hospice—Barriers to Care

Identifying causes and patterns of death provides a starting place to consider what systems of care are needed for different causes and patterns of dying. Like the general U.S. population, most causes of death among all California's populations are due to serious chronic illnesses and terminal conditions for which traditional models of EOL care are designed and implemented. For these deaths, the hospice model has been considered the gold standard for care of the dying.

This assumption is now being questioned. Payment and reimbursement systems for hospice and palliative care have created barriers for some racial/ethnic populations, including the Medicare Hospice Benefit requirements that force patients and families to make dichotomous choices—decisions that may appear to be between life and death. Needing to choose between accepting hospice and comfort care to the exclusion of life-extending or potentially curing interventions presumes that patients are willing to accept a limited prognosis and to embrace dying—an assumption that may conflict with some cultural beliefs and values.

Other barriers to hospice use may include the absence of culturally and linguistically appropriate services. This latter problem has been laudably addressed in California. Large hospices and those located in multi-ethnic communities have been more successful in offering culturally appropriate services than small independent hospices or those in mostly White communities. However, many immigrants face an additional barrier to hospice because they're not eligible for most federal and state health care benefits.

EOL Care in Emergency Settings

In California, younger persons who are Latino, Native American, or African American die disproportionately from unexpected, sudden deaths due to accidents and assaults. While this strongly suggests that the state increase interventions in public health prevention and acute and emergency clinical care, one cannot realistically expect that all deaths from these events will be completely eradicated. People will still die from car accidents, gunshot wounds, falls, and other traumatic incidents. They will need EOL care, and their families and loved ones will need bereavement care services. Improving EOL care in emergency settings would benefit all Californians.

Find Your Friend: Culturally Appropriate Advance Care Planning

All persons, regardless of race or ethnicity, may face challenges in decision-making and ethical quandaries related to EOL care delivery, but the chances for conflicts increase when patients and providers do not share the inherent values represented by bioethics practices in this country. Advance care planning, another gold standard in EOL care, may not be valued or understood by certain ethnic communities, particularly those who may consider discussion of death to be taboo. This does not mean that we, as a society, should abandon the goals of determining patient values and preferences for care at the end of life, but rather adopt approaches that are more culturally appropriate.

This report highlights one community-based project, undertaken by Oakland's Ethnic Health Institute, that developed and implemented a culturally acceptable alternative to advance directives for African Americans. This project reframed discussions about preference for dying to encourage the designation of a family member or friend who would know an individual's values should the need for surrogate decision-making arise.

Provider Training for Pain Management

A competent and skilled workforce is paramount for providing quality EOL care for all Californians. AB 487, the Pain Management and Appropriate Care and Treatment of the Terminally Ill bill that requires physicians to complete continuing education in this area, was an effort to improve the knowledge base of physicians in the state. Most unfortunately, the law did not require, and many educational providers offering courses did not include, any curriculum on racial/ethnic disparities in pain or on topics related to pain and suffering as culturally mediated processes. In addition, there has been little to no oversight regarding the quality of courses and content that meet the requirements of AB 487.

If the state continues to mandate provider education in pain and palliative care beyond the 2006 deadline, new legislation that went into effect in January 2006 (the Cultural and Linguistic Competency for Doctors bill, AB 1195, requires that all future Continuing Medical Education programs contain a cultural competency component) may address the concern of inadequate education in ethno-cultural aspects of pain management and EOL care. But this should be monitored to insure that the health care community prepares a medical workforce competent to provide equitable, competent, and culturally and linguistically appropriate EOL care.

Other regulatory bodies should follow the lead of the California Medical Board. Pharmacists, who are also required to complete ongoing continuing education, may be an important link in the causal chain for inadequate pain management among ethnic/racial groups and would benefit from mandates similar to AB 1195.

Communication and Trust

Ethnically diverse patient populations require a health care workforce that can provide culturally and linguistically appropriate services such as those recommended by the U.S. Department of Health and Human Services Office of Minority Health. Workforce issues, including limited numbers of trained and available translators across health care settings, compromise quality care for the state's monolingual non-English-speaking patients and families. Poor or miscommunication may engender mistrust, a problem reported by many providers who work in cross-cultural settings.

The authors have observed that trust or mistrust is not the solitary experience of the patient, but rather the outcome of a process involving at least two parties — the one who trusts and the one who is trusted. Both parties bear some responsibility for the outcome of interactions. Cultivating trust requires all members of the health care delivery system to examine their own trustworthy or untrustworthy actions and intentions.

Although California boasts being the most diverse state in the country, racial and ethnic populations are still at risk of experiencing bias in health care. As described in the Institute of Medicine report on unequal treatment, bias, stereotyping, and prejudice are processes that have causal mechanisms that may exist at patient, provider, or systems levels. The authors observed interactions in which miscommunication and mistreatment of patients by providers was not likely the result of overt, conscious, or intentional acts of racism by the providers, but rather the unconscious acts resulting from provider burnout. There were tremendous burdens placed on one observed public health facility, including serious reductions in available services, that in turn overwhelmed the workload of otherwise dedicated health care workers.

A Promising Health Care Workforce Training Model

Preparing a workforce to provide equitable, competent, and culturally and linguistically appropriate EOL care will require training models that address a range of critical issues. This report highlights an innovative model for training, the ACCESS program administered through VISIONS Inc., which may be a rich resource for training across key elements of EOL care through an effective framework grounded in multiculturalism.

Recognizing the Individual

Although this project for the California HealthCare Foundation had the goal of focusing on race, ethnicity, and culture in EOL care, one must acknowledge a potential paradox: while respecting differences among California's various populations, there is always a risk of essentializing groups and stereotyping individuals. By essentializing, that is to presume that all members of a group are the same, one may fail to acknowledge that individuals inhabit multiple socio-demographic identities simultaneously and that movement among these identities is fluid depending on need or the particularities of circumstances. It follows, then, that there are situations or circumstances where membership in a racial, ethnic, or cultural group would not be the only factor influencing EOL care.

Improving EOL Care for Subgroups Benefits Everyone

While the goal of this report was to focus on recommendations to improve EOL care for the state's ethnically, racially, and culturally diverse populations, any efforts to improve care for the dying patient or family will most likely positively affect the care of all persons, regardless of ethnicity or race. Conversely, efforts targeting care for diverse population groups—attending to and eliminating causes of disparities, creating and supporting culturally appropriate health delivery systems, improving processes of decision-making across cultures, addressing ethno-cultural aspects of pain and symptom control, and generally improving communication and trustworthiness—will likely result in a care system that will benefit all of California's residents.

Recommendations

Policy/Regulation

- Encourage public health officials to include improving quality of dying in their prevention priorities.
- Support strategies that encourage and increase the number of care delivery institutions that provide culturally and linguistically appropriate services by incorporating guidelines developed by the U.S. Department of Health and Human Services Office of Minority Health.
- Support education and training programs for emergency personnel on unique issues of death and dying in EMS and emergency department settings.
- Mandate continuing education modules that specifically address cultural diversity in decision-making as part of AB487 extension.
- Consider extending the requirement for periodic continuing education in pain management and palliative care for all state-licensed physicians beyond the December 31, 2006 deadline.
- Require and provide oversight to insure that all future continuing medical education courses and curricula include modules on ethno-cultural aspects of pain and palliative care.
- Create legislation similar to AB 1995, the Cultural and Linguistic Competency Bill for physicians, that creates cultural competency education mandates for pharmacists and other state-licensed providers engaged in EOL care.
- Establish training and continuing education requirements similar to AB487 for all other health professionals involved in EOL and palliative care (such as nurses, social workers, pharmacists, and respiratory therapists).

- Develop mechanisms for quality monitoring and development of culturally and linguistically appropriate service improvement strategies for providers and institutions.
- Providers, institutions, and organizations in the field of palliative and EOL care should consider the public health implications of death and dying among immigrants in the United States to understand the morbidity and mortality patterns and disparity implications for these populations and to advocate for public policy beneficial to immigrant patients and their families.
- Bi-national structures that are already in place such as the California Office of Bi-national Border Health and the United States–Mexico Border Health Commission (the latter has adopted the Healthy Border 2010 program) should be lobbied to include EOL care in their health promotion and disease prevention agendas.[1–3]
- Pending comprehensive immigration reform, care needs for all persons facing the end of life should be covered by public benefits..

Payers/Purchasers

- Find alternative funding strategies, including reform of Medicare Hospice Benefit restrictions, to allow for appropriate aggressive treatments while receiving palliative care coverage when such treatments and interventions stand to enhance patients' lives.
- Support Pay for Performance strategies applied to the care of dying patients to improve quality EOL care.

Providers

- Increase knowledge and use of evidence-based appropriate medical treatment.
- Increase number of hospitals and nursing homes with quality palliative care services.
- Provide continuity, coordination, and comprehensiveness of essential services in every community.
- Enhance strategies to improve EOL decision-making, such as advance planning and other communication strategies.
- Increase and improve bereavement services and resources in emergency settings.
- Create opportunities for dialogue among coroner's offices, law enforcement officials, emergency departments, and bereavement care or other EOL care providers, institutions, and organizations for improving EOL emergency room experiences for families.
- Create systems of referral through emergency departments for bereavement services.
- Minimally, safety net delivery systems should be supported and expanded to include EOL and palliative care services.

Funders

- Fund demonstration projects that model best practices of community-based EOL decision-making strategies.
- Encourage funding for hospital ethics committee training on cultural diversity in EOL values and perspectives.
- Fund faculty development and expansion for programs like ACCESS.
- Fund train-the-trainer programs to increase the reach and influence of programs like ACCESS.
- Include support for programs to continually revise and update culturally appropriate EOL/palliative care curricula.

Other Stakeholders

- Expand approach from limited individualized care strategies that dominate the EOL care field to include population-based implications of death and dying.
- Use death trajectory models to identify needs of dying patients and families.
- Encourage use of population-based models to ensure such coordination and continuity.
- Create mechanisms for partnership building between programs like ACCESS and other EOL coalitions (i.e., California Coalition for Compassionate Care).
- Other initiatives should include cross-national efforts to collaborate on research, education, and health care delivery that may affect or improve palliative care in the home countries of California's immigrants.
- To combat discrimination and exploitation of immigrant health care workers and home caregivers, health care facilities should develop and implement assimilation programs to integrate new nurses into the existing culture and to educate existing employees about the far-reaching benefits of cultural diversity.

II. Background

Identifying patterns of death among California's racial, cultural, and ethnic communities is the first step in identifying care needs at the end of life.

Who Dies in California?

End-of-life (EOL) care is the medical, social, psychological, spiritual, and financial care and attention provided to persons and their families who are facing death. Making good quality care available for those who will die requires knowledge of this target population.[4] Identifying patterns of death among California's racial, cultural, and ethnic communities is the first step in identifying care needs at the end of life.

Who dies in California? In 2004, 235,300 Californians died.[5] The most populous state in the country, California is also the most ethnically and racially diverse. Differential rates of death exist among the varied population groups who live in the state.

The California estimated age-adjusted death rate for 2004 was about 724 deaths per 100,000 persons (using 2000 U.S. standard population).[6] This was less than the national estimate of 801 deaths per 100,000.[7] As shown in Table 1, African Americans and Native Americans in California had significantly higher age-adjusted death rates. African Americans had 1.4, 1.6, and nearly 3 times the rates of Whites, Latinos, and Asian Americans, respectively, while Native Americans had nearly 2 times the age-adjusted death rates of Whites and Latinos and 3.5 times the rate of Asian Americans. Asian Americans had the lowest death rate of all groups.

Table 1. Death by Race/Ethnicity, 2004 California

RACE/ ETHNICITY*	% TOTAL POPULATION	NUMBER OF DEATHS	AGE-ADJUSTED RATE PER 100K†
White, Non-Latino	44.5%	164,674	814.5
Latino	34.7%	33,701	739.5
Asian American	12.1%	10,964	411.8
African American	6.8%	18,592	1145.8
Native American	1.2%	1,902	1434
TOTAL	99.3%‡	229,833	723.7

*Excludes Pacific Islanders, race/ethnicity unidentified, or those categorized as other.

†Number of deaths per 100,000 population, age-adjusted to 2000 U.S. Population Standard. Rates allow for standard comparisons across different racial/ethnic groups.

‡Total reflects the exclusion of subgroups listed.

Sources: Center for Health Statistics, Death Statistical Master Files; U.S. Bureau of the Census Population Data.

Data Limitations

The information to be gleaned from this data is limited by the fact that it reflects the collapsing of several distinct communities into single population groups. For example, Latinos are persons with ancestry from countries in Latin America, Spain, or the Caribbean who represent the full range of "racial" categories. Similarly, the Asian category consists of persons from a range of disparate nationalities. Because national data is reported based on five single broad categories of race and one dichotomous category of ethnicity (Latino or non-Latino), it is difficult to calculate age-adjusted death rates for subgroups within California's multi-ethnic populations. However, state death records do report causes of death using disaggregated racial and ethnic categories. (See Appendix A in the supplemental report for causes of death across Latino and Asian American subgroups.)

Immigration's Influence

It is also important to understand the effects of immigration status on EOL care in California. Immigrants are among the fastest growing population in the United States. If current growth trends continue, nearly two-thirds of the population in 2050 will be immigrants. The largest growing segment of immigrants includes those who have entered this country illegally or who have overstayed their visas. They are referred to as undocumented, unauthorized, or illegal and are ineligible for most federal benefits except for care that is deemed emergency and life-threatening. In California, estimates suggest that over 2,500,000 undocumented immigrants reside in the state (27 percent of the nation's undocumented population), with major concentrations in both the Bay Area and Los Angeles regions. The vast majority of these immigrants are from Mexico. As Mexicans represent the largest immigrant group in California, findings in this report focus primarily on Mexican (Latino) immigrant issues.

Greater than 25 percent of these undocumented persons are between ages 15 to 44 years and come to the United States primarily looking for work or other opportunities. Most are part-time or temporary workers without employment-based insurance.[8] They are generally a healthy population when they arrive in the United States.[9] These younger immigrants may decide to stay in the United States due to difficulties with re-entry once they leave or because of lack of opportunities in their home country.[10] Other reasons to stay may include ties to extended intergenerational familial networks. Thus, those who stay permanently may eventually become part of the cohort of aging adults. In California, elderly immigrants (primarily Asian and Latino) make up 20 percent of the state's senior population.[11] According to Census projections, this figure is expected to rise considerably over the next few decades.[12] These projections may need adjustment to account for return emigration by some individuals to their native countries.

Age of Death Varies by Subgroup

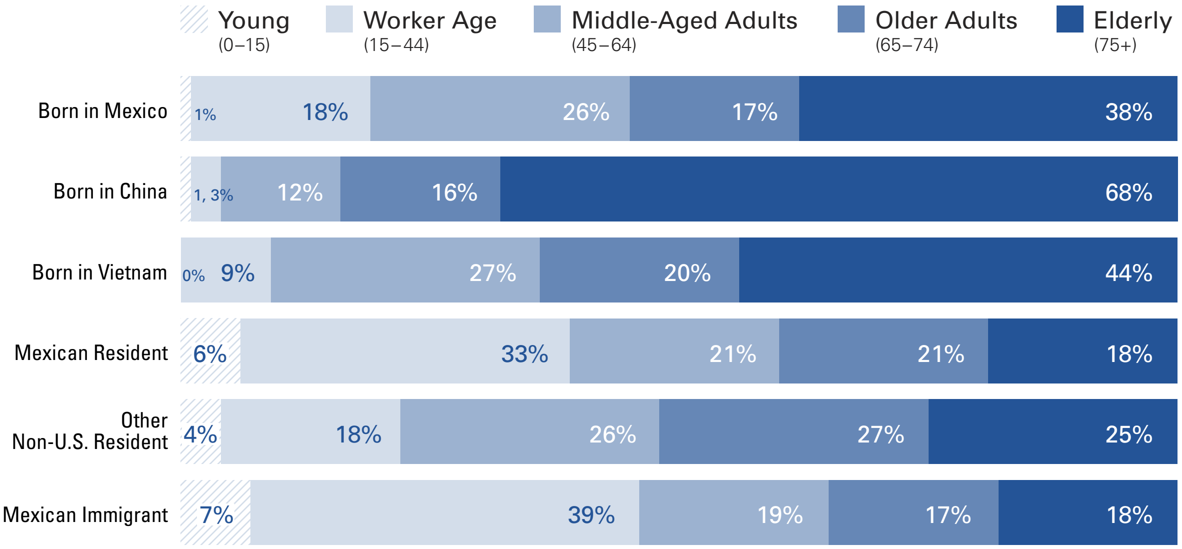
Analysis of the 2004 California Death Statistical Master Files suggests that the distribution of age at death varies among California's ethnic immigrant sub-populations. (See Figure 1.) For example, deaths among persons born in China occurred in a much older age group than those born in Mexico. A large proportion of deaths (58 percent) among Mexican-born Mexican residents occurred in the age group of 15 to 64 years (working and middle age). This finding suggests that while immigrants may arrive in California in relatively good health, some will face dire circumstances that may lead to death.

What Do Californians Die From?

The leading causes of death for Californians in 2004 are shown in Table 2.

When stratified by race and Latino ethnicity, each population bears unique, additional burdens from diseases that are not among the top ten causes of death for others. For example, uniquely among African Americans (and no other aggregated population group), HIV is among the top ten causes of deaths. Among Asian Americans, infectious

Figure 1. Age at Death by Birthplace, Residence, or Mexican Immigrant Status*



*For an explanation of non-U.S. status categories, see section: Epidemiology of Death Among Immigrants in California. Data on Mexican immigrant status is based on proxy calculations determined by birthplace and official residence at time of death.

Source: Center for Health Statistics, Death Statistical Master Files.

Table 2. Leading Causes of Death and Share of Total Number, by Race in California, 2004

	ALL PERSONS		WHITE		LATINO		ASIAN AMERICAN		AFRICAN AMERICAN		NATIVE AMERICAN /ALASKAN NATIVE	
CAUSE OF DEATH	**Rank**	**% of Total**	**Rank**	**% of Total**	**Rank**	**% of Total**	**Rank**	**% of Total**	**Rank**	**% of Total**	**Rank**	**% of Total**
Heart Disease	1	31%	1	32%	1	25%	2	26%	1	31%	1	28%
Cancer	2	25%	2	25%	2	21%	1	31%	2	24%	2	22%
Cerebrovascular Disease	3	9%	3	9%	4	8%	3	12%	4	9%	4	4%
Trauma and Other External Causes	4	8%	5	6%	3	14%	4	8%	3	10%	3	13%
Chronic Respiratory Disease	5	7%	4	8%	7	4%	5	5%	5	5%	5	6%
Alzheimer's and Other Nervous System Diseases	6	5%	6	6%	8	3%	7	3%	7	3%	8	3%
Diabetes	7	3%	7	2%	5	6%	6	4%	6	5%	7	5%
Dementia/Organic Mental Diseases	8	2%	8	2%	—	—	—	—	9	<2%	9	<2%
Chronic Liver Disease and Cirrhosis	9	2%	10	<2%	6	4%	—	—	—	—	6	5%
Diseases of the GI System	10	2%	—	—	—	—	10	<2%	—	—	10	<2%
Nephritis	—	<2%	9	<2%	10	2%	8	2%	8	2%	—	—
HIV Disease	—	<1%	—	—	—	—	—	—	10	<2%	—	—
Infectious Disease	—	1%	—	—	—	—	9	<2%	—	—	—	—
Perinatal	—	<1%	—	—	9	2%	—	—	—	—	—	—

Source: Center for Health Statistics, Death Statistical Master Files.

diseases and among Latinos, perinatal conditions are among the unique top ten causes of death for each of these groups.

Patterns of Death for Subgroups

When looking at sub-populations, other patterns emerge. (See Appendix A.) For example, although perinatal conditions were among the leading causes of death for Latinos as a whole, this was not the case for Cubans or Puerto Ricans. HIV/AIDS was not counted among the top ten causes of deaths for Latinos as a whole, but was included among deaths for Puerto Ricans and Central/South Americans. Among Asian Americans, a top ten cause of death includes diseases of the GI system. However, this was a leading cause of death for Chinese and no other subgroup of Asian Americans. Persons of Japanese ancestry died from dementia; Laotians died from inflammatory musculoskeletal diseases, perinatal, and congenital conditions; Koreans and Southeast Asian groups (Cambodians, Vietnamese, Laotians, and Hmong) died from cirrhosis and other liver diseases; and Cambodians and Thais died from HIV/AIDS. These varied causes of death among Asian American subgroups do not fall within the top ten causes of death when aggregated under the larger Asian racial category.

Death Among Immigrants in California. Death data collected by the Office of Health Information and Research of the California Department of Health Services does not include citizenship status; therefore, the authors could not accurately determine the immigrant status of California decedents based on information compiled from death certificates.

One can, however, make proxy assumptions based on place of birth and stated residence at the time of death. The authors analyzed data based on where the decedent was born; the official residence at the time of death; and, among non-U.S. born persons who were registered residents of California, location of death (even deaths that occurred outside of the country) from data available in the Death Statistical Master Files maintained by the Center for Health Statistics. These proxies for immigration status enabled the authors to examine patterns and trends within this population, but it is unknown if these persons were full-fledged citizens, eligible for the range of state and federal benefits for EOL or other palliative care needs. See Tables 3 to 5.

Table 4. Top Three Causes of Death in California, by Residence at Time of Death

	ALL PERSONS		MEXICO		OTHER COUNTRIES	
CAUSE OF DEATH		% of Total	Rank	% of Total	Rank	% of Total
Heart Disease	1	31%	2	16%	1	39%
Cancer	2	25%	3	15%	2	25%
Trauma and Accidents	4	8%	1	40%	3	16%

Source: Center for Health Statistics, Death Statistical Master Files.

Table 3. Top Five Causes of Death, by Birthplace

	ALL PERSONS		CHINA		CUBA		MEXICO		PHILIPPINES		VIETNAM	
CAUSE OF DEATH	Rank	% of Total	Rank	% of Total	Rank	% of Total	Rank	% of Total	Rank	% of Total	Rank	% of Total
Heart Disease	1	31%	2	27%	1	36%	1	27%	1	33%	2	24%
Cancer	2	25%	1	33%	2	24%	2	23%	2	28%	1	35%
Cerebrovascular Disease	3	9%	3	14%	3	8%	4	9%	3	13%	3	12%
Trauma and Accidents	4	8%	5	5%	—	—	3	14%	—	—	4	8%
Chronic Respiratory Disease	5	7%	4	6%	4	7%	—	—	4	6%	5	5%
Diabetes	7	3%	—	—	5	6%	5	6%	5	5%	—	—

Source: Center for Health Statistics, Death Statistical Master Files.

Table 5. Top Causes of Death in California, by Mexican Birth AND Residence*

CAUSE OF DEATH	ALL PERSONS		MEXICO BIRTH/ RESIDENCE	
	Rank	% of Total	Rank	% of Total
Heart Disease	1	31%	2	17%
Cancer	2	25%	3	11%
Trauma and Accidents	4	8%	1	45%

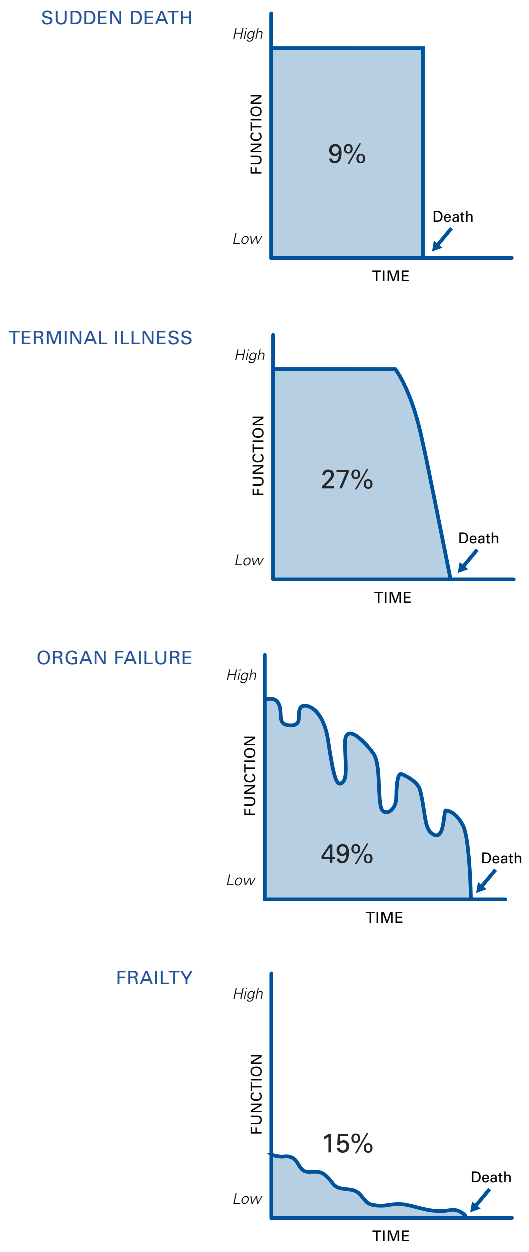
*Proxy for Mexican immigrant status.
Source: Center for Health Statistics, Death Statistical Master Files.

Implications for EOL Care for Immigrants. In 2004, the top causes of death in California for persons born in China, Mexico, the Philippines, and Vietnam were similar to patterns for the state's multi-ethnic populations (Asian Americans and Latinos). The exception is the pattern for Cuban-born decedents (where trauma was not among the top five causes of death). (See Table 3.) Of significance in causes of death by residence is the finding of trauma and accidents as the number one cause of deaths among Mexican residents.

How Do Californians Die? Death Trajectories

In some cases death can be the predictable culminating event following advanced age or certain illnesses. In others, it may appear suddenly or unexpectedly after trauma or from a health condition whose trajectory is unpredictable. Dying—the range of events preceding death—is a temporal process. The care required to attend to the needs of dying patients and their families is, among other things, a function of timing that reflects the natural history or *trajectory of the underlying cause of death.*[13, 14] (See Figure 2.)

Figure 2. Patterns (Trajectories) of Dying and Share of California Deaths, 2004



Sources: Lunney et al., Patterns of Functional Decline; Chan, End-of-life models; Center for Health Statistics, Death Statistical Master Files.

- **Sudden, unexpected deaths** (9 percent of deaths in 2004) are marked by prior states of high functioning followed by an abrupt event, such as a motor vehicle accident, suicide, or gunshot wound.
- Individuals with a diagnosis of cancer often follow the trajectory of **terminal illness** (27 percent of deaths), where there is some period of high

to fairly high functioning, after which there is commonly a predictable course of decline, leading to death. The Medicare Hospice Benefit eligibility, which requires a terminal prognosis of 6 months or less, is based on this trajectory pattern.

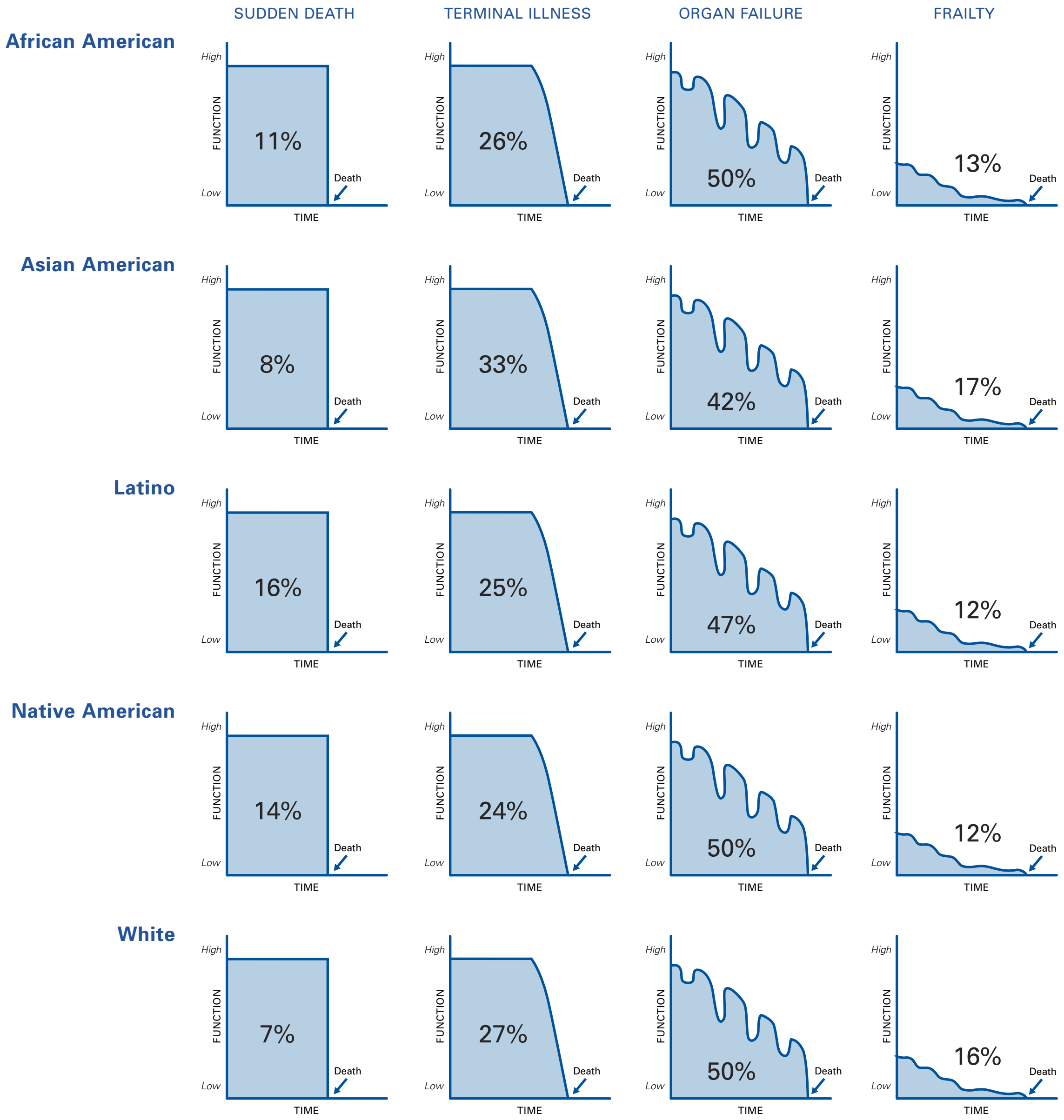
- The trajectory of **organ failure** (49 percent of deaths), associated with chronic, eventually fatal conditions, is one of compromised functioning followed by a decline punctuated by periods of acute, sudden deterioration with recovery to a lower level of functioning. A significant result of this pattern is that patients, families, or even providers cannot always predict which sudden episode of decline will result in recovery or death; in addition, experiences with previous recoveries may cause patients or families to insist on aggressive, resource-intensive treatments even at the point when decline toward death is imminent.
- Lastly, patterns of **frailty** (15 percent of deaths), such as those seen among the eldest elderly or patients suffering from strokes or Alzheimer's disease, begin with low functioning followed by a prolonged decline toward death.

Racial/Ethnic Trajectories of Death[15]

Trajectory patterns for deaths in 2004 among different racial/ethnic populations in California are similar to the patterns shown for all Californians with the exception of deaths following suddenly from trauma, accidents, or other unexpected events. (See Figure 3.) While trajectories that follow a *sudden pattern* constitute 7 to 8 percent for Whites and Asian Americans, they *represent a larger percent of deaths for Latinos, African Americans, and Native Americans.* Most significantly, unique among Latinos, Mexican immigrants, and Native Americans is the higher percent of sudden deaths (which disproportionately affect younger persons) over the percent of deaths associated with frailty (which generally affect older persons).

The authors calculated proportions of death by trajectory type for Mexican resident vs. other non-U.S. resident deaths and found striking differences (figures not shown). Sudden, unexpected deaths made up 44 percent of deaths for Mexican residents vs. 17 percent for other non-U.S. resident deaths. By contrast deaths from chronic disease made up 30 percent for Mexican residents vs. 48 percent for other non-U.S. residents.

Figure 3. Patterns (Trajectories) of Dying and Share of Deaths, by Race/Ethnicity, 2004



Sources: Lunney et al., Patterns of Functional Decline; Chan, End-of-life models; Center for Health Statistics, Death Statistical Master Files.

III. Systems of Care Available or Needed at the End of Life

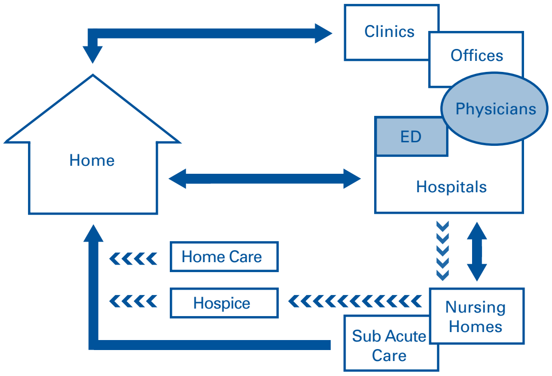
> *"We had a referral of a patient from home health that we wanted to refer to a hospice agency in town. She was an African American female, a young girl who was dying of end-stage cervical cancer, and hospice took the referral, called us back, and said they weren't going to take her because she lived in a bad end of town in a motel, and was, they thought, 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… They refused to take her care and actually she subsequently went into the hospital, so sometimes we maybe judge safety or make judgments that—I know we have to protect ourselves and that's important, too. But I think sometimes we also have to take a look at the reality of people's lives and see what we can do to provide compassionate care…"*
>
> —DISCUSSION AMONG FOCUS GROUP PARTICIPANTS, FRESNO

Health Service Delivery Implications of Trajectories of Dying

The significance of these trajectories relates to the implications for care needs for distinct patterns of dying. The health system needs of a patient dying from a prognostically predictable condition, such as those seen in terminal patterns, differ from the needs of someone whose dying follows a sudden trajectory. (See Figure 4 and Table 6.)

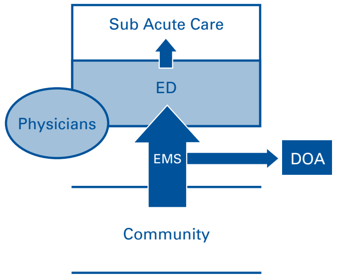
Figure 4. Systems of Care

Patients with Terminal Illness, Organ Failure, or Frailty Trajectory Patterns*



From home, patients enter the health care system (clinics, offices, emergency departments, hospitals, nursing homes, or sub-acute facilities) for acute, emergency, or chronic care services to be referred to home care or hospice, or to re-enter other parts of the system, as needed and determined by gatekeepers (physicians).

Patients with Sudden Death Trajectory Pattern



From the community or home, patients enter the health care system through the emergency department via EMS or other community-based conveyances. They may require emergency operating room or intensive care services prior to death.

*Source: Morrison, R.S. Health care system factors affecting end-of-life care. *Journal of Palliative Medicine.* 2005; 8 Suppl 1:S79–87.

Table 6. EOL Care Services Used, by Type of Death Trajectory

EOL CARE SERVICE	SUDDEN DEATH	TERMINAL ILLNESS	ORGAN FAILURE	FRAILTY
EMT services	√	√	√	√
Acute care beds	√	√	√	√
Operating rooms	√	√	√	
Life-saving or extending measures	√	√	√	
Physician services*	√	√	√	√
Drugs and biologicals‡	√	√	√	√
Family bereavement counseling	√	√	√	√
Short-term inpatient care		√	√	√
Skilled nursing care		√	√	√
Home health care†		√	√	√
Social services		√	√	√
Patient counseling (dietary, spiritual, and other)		√	√	√
Home medical appliances and supplies		√	√	√

Patients enrolled in hospice…

░ are eligible for these services under the Medicare Hospice Benefit. ▓ who use these services risk loss of Medicare Hospice Benefit.

√ Services used by dying patients and/or their families.

*Physician services include the range of primary and specialty care; eligibility for reimbursement varies based on conditions and coverage. For example, the Medicare Hospice Benefit covers most primary and palliative care provider services but not ineligible hospital, emergency, or surgical provider services.

†Home health care includes homemaker services; home health aide services; therapy (physical, occupational, and speech); and inpatient respite care.

‡The Medicare Hospice Benefit will cover drugs and biologicals used for pain control and symptom management.

Where Do Californians Die?

Data reported here on California deaths in 2004 from The Center for Health Statistics do not illustrate specifics of the so-called "salmon effect," where non-native born Americans or immigrants living in California and using the state's EOL care resources return to their home country to die.[16] Among those who did die in California, the data show broad patterns of home versus institutionalized deaths.[17] (See Table 7.)

Dying at Home

Approximately one-quarter of California deaths in 2004 occurred at home. However, death certificate data does not provide sufficient detail to determine what proportion of these home deaths were hospice enrollees receiving skilled nursing, medical, and home health care consistent with hospice practices vs. those who died at home without receiving these services. Although some studies have reported home as the preferred site of death for many persons, this

Table 7. Site of Death Among Californians (and Share of Total Deaths), by Racial/Ethnic Group, 2004

RACIAL/ETHNIC GROUP	HOME*	HOSPICE*	HOSPITAL	NURSING HOME
White	48,894 (29.7%)	1,489 (0.90%)	65,959 (40.0%)	37,376 (22.7%)
Latino	8,083 (24.0%)	300 (0.89%)	18,827 (55.8%)	3,542 (10.5%)
Asian American	2,488 (22.7%)	83 (0.76%)	6,115 (55.8%)	1,697 (15.5%)
African American	4,164 (22.4%)	123 (0.66%)	10,625 (57.1%)	2,377 (12.8%)

*Data obtained from death certificates was recorded as either death occurring in a licensed hospice facility or in a decedent's home; therefore, some home deaths may also be hospice deaths.

Source: Center for Health Statistics, Death Statistical Master Files.

finding conflicts with reports on the desire among some groups (African Americans and Latinos) for resource-intensive, life-saving interventions that can only be administered in institutional settings.[18–21]

Dying in Hospice and Palliative Care Settings

To date, only two models of service delivery have focused almost exclusively on dying patients and their families. Hospice, considered the gold standard for care of the dying, and palliative medicine (sometimes referred to as comfort care) are philosophies of care as well as a spectrum of structured services. While both can be offered across settings, from home to skilled nursing to inpatient facilities, only the former, hospice, is eligible for federal reimbursement through the Medicare Hospice Benefit.[22, 23]

The regulations associated with this benefit, notably, have been shown to create barriers to care for some racial/ethnic populations. For example, the requirement of a prognosis of six months or less and the agreement to waive Part A Medicare benefits (which may include curative treatments) in order to enroll in hospice may run counter to African American and Latino general preferences for resource-intensive, life-prolonging therapies that are not covered under the Hospice Benefit. Hospices, particularly smaller independent programs, may institute restrictive admission policies such as not admitting persons who are unwilling to forgo hospitalization or those who receive or would request complex medical care (including artificial feeding, or chemotherapy).[24] These practices may conflict with culture-based preferences.

> *"…if we want to change the culture of hospice, it has to be viewed as we are giving the family something instead of taking away treatment… It is only going to be for this little bit, you know, why not palliation, radiation, for a little bit? Why not chemo for a little bit? Because Medicare only has a certain set of money for this, but the more innovative hospices out there are getting the majority of the patients because they know it is only going to be for this much, for this long. So maybe changing the hospice view about taking everything away, maybe more people will give into it more instead of two weeks before, two days before, maybe they will join up a year before."*
>
> — FOCUS GROUP PARTICIPANT, LOS ANGELES

An alternative to the limits of the Medicare Hospice Benefit is private insurance coverage for palliative care services. However, this is not uniformly available. Patients who are unable to afford private insurance may receive charity (unreimbursed) hospice care at some not-for-profit and freestanding hospices.[25]

> *"Sometimes it can get difficult when there are financial considerations. Some insurance companies have a very limited benefit and so some people who were dying and who do a lot of reading and research on hospice, those people, some people with private insurance don't get the benefits that the people with [other kinds of] insurance do. So talking to families and they say, 'Well, what about this' and [you have to reply], 'Sorry, your insurance doesn't cover it.' It can be very difficult, very uncomfortable."*
>
> — FOCUS GROUP PARTICIPANT, LOS ANGELES

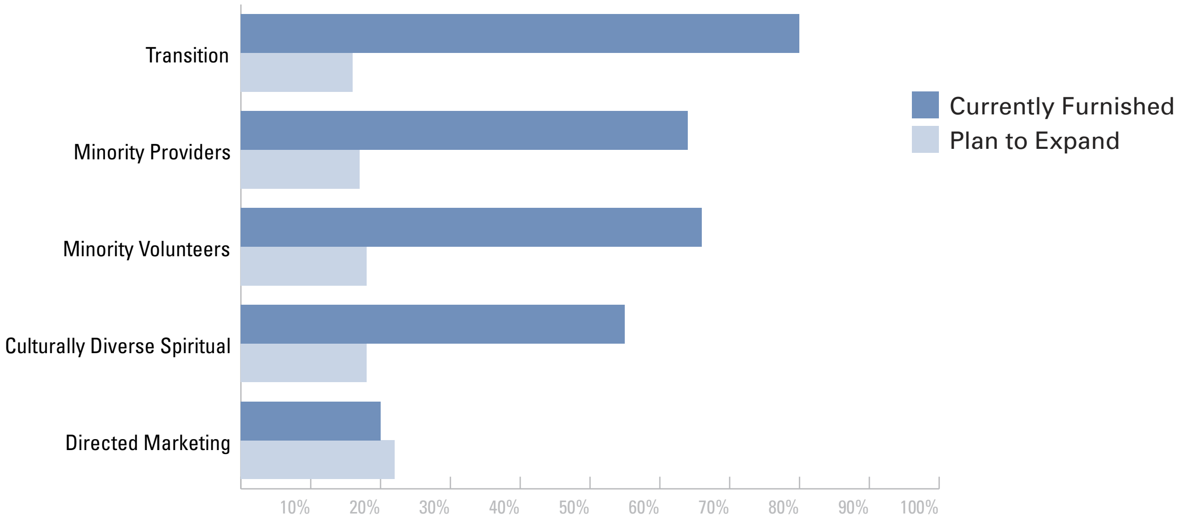
In our focus group discussions, the authors heard of hospices that may discriminate against patients because of staff fears, stereotyping, and prejudices, which can be compounded by the lack of resources to provide culturally appropriate care.

Other barriers to hospice use may include lack of culturally and linguistically appropriate services. This problem has been laudably addressed in California. (See Figure 6.) In a survey of 149 hospices across the state, investigators found that many programs are making efforts to serve the needs of ethnically and racially diverse patients, offering such services as translation, ethnically/racially diverse providers and volunteers, and faith-based services. Larger hospices and those located in multi-ethnic communities have been shown to be more likely to offer culturally appropriate services than those in mostly White communities. Smaller hospices in the state that are unaffiliated with large chain operations, however, are less likely to provide these services than larger hospices.[26] It should be noted that survey responses regarding the use of translation or interpreter services do not reveal quality indicators of these services. Survey data do not reveal information about the quality of training or interpretation, the availability and accessibility of services (24-hours; weekends), nor how these services are delivered (in-person vs. telephone).

Nationally, ethnically diverse persons are still less likely than Whites to use hospice.[27–29] Similarly, California still faces challenges to improving access. Data from 2004[30] show that the percent of Latino, Asian American, and African American patients who died in hospice was 15, 4, and 6 percent of the total hospice deaths, respectively, compared to 74 percent for Whites.

Furthermore, most deaths for all immigrants occurred in in-patient hospital settings. Few used hospice for their EOL care needs. This may reflect, in part, lack of eligibility for hospice benefits; it may be due to lack of cultural acceptance of hospice; or it may indicate other cultural trends (such as the "Salmon effect," mentioned earlier, where immigrants return home to their native countries to die[31]).

Figure 6. Culturally Appropriate Services in California Hospices*



*Proportion that currently offer or are planning services that might affect minority participation.

Source: Lorenz et al., Accommodating ethnic diversity.

In addition, data on patterns of death (or death trajectories) suggest that hospice is not appropriate for all deaths. The hospice model cannot address the needs of patients and families dying from acute traumatic or other unexpected events—the pattern of death that affects a disproportionate number of Latino, African, and Native Americans, as well as Mexican immigrants.

Dying in Hospitals, Emergency Departments, and Skilled Nursing Facilities

As the majority of deaths occur in hospitals and nursing homes, it follows that most EOL work occurs primarily in institutional settings. Yet less than half of California hospitals and fewer skilled nursing facilities offer some type of palliative care service.[32] In addition, given that a substantial number of deaths occur in emergency and intensive care settings where the focus of care is on acute, aggressive, life-saving interventions, the needs of dying patients and their families may be compromised in such settings.

> *"How about the ones that I see in the emergency room who have advance directives and [the emergency room staff] have gone ahead and intubated them?… Then the family members come in all sad and say why should they have an advance directive?"*
>
> —FOCUS GROUP PARTICIPANT, LOS ANGELES

Ethno-cultural Preferences. Some populations may prefer continued life-extending interventions even in light of conditions with limited prognosis.[33–35] As these treatments are usually delivered in hospital settings, the honoring of this preference would increase the likelihood of dying in hospitals—an outcome that may indeed meet the preferences of persons who would rather die in an institution than at home. This suggests a further call for the need to bring quality palliative care to hospitals, emergency rooms, and nursing homes.

> *"I work in a [large hospital] so there is such a thing as length of stay. That is where the patient has been here 67 days and [the administration pressures us, asking] what are we doing to get them out? What are we going to do to get them out? I stopped spinning my wheels when it comes to certain cultures. Certain cultures you just let them be. They will die in the hospital. This is what they do. I used to get frustrated and wanted to find an angle [to get them discharged], but it was only to please [hospital administrators]."*
>
> —FOCUS GROUP PARTICIPANT, LOS ANGELES

Challenges to providing quality EOL care in both emergency and critical care settings include "variability in practice, inadequate predictive models for death, elusive knowledge of patient preferences, poor communication between staff and surrogates, insufficient or absent training of health care providers, the use of imprecise and insensitive terminology, and incomplete documentation in the medical records."[36, 37]

> *"[There was] an emergency room case: a male Latino minor came with a gunshot wound to the head. The social worker was able to get the physician to come …to tell the family, 'He's in bad shape, we're doing everything we can, but I don't think it's going to happen.' At this point the family was not allowed to see the minor, because they didn't want [them] to get in the way of whatever medical intervention was taking place. This mother sat in that [waiting] room for a period of about an hour with no other update on her son until about five minutes prior to his death. The physician came out again and said,*

'You know, it really looks really, really bad,' and this woman hadn't seen her son throughout the whole ordeal. [The doctor] stepped out, and as he stepped out they pronounced him. Because of the nature of the injury it became a coroner's case so it became an issue of, 'Well, I'm sorry, Mom, but you cannot see your dead son.'"

— FOCUS GROUP PARTICIPANT, FRESNO

Among recommended policies, the American College of Emergency Physicians has asserted the goal to "help patients and their families achieve greater control over the dying process" as a means to improve EOL care. As a part of that control, families and loved ones need to be given the proper opportunity to grieve. One can only imagine the anguish experienced by the mother in the above story, compounded by a total lack of control in her son's dying process. The legal mandate in forensic cases requires maintenance of the decedent's body and preservation of the resuscitation setting for forensic investigation. Reducing the victim to "evidence" and the health care setting to a crime scene, however, can severely impede quality of EOL care.[38] Furthermore, EOL care does not end at death. Bereavement is an important part of the death and dying process. To address the needs of the bereaved, acceptable compromises should be sought by law enforcement and emergency personnel, as well as other health providers, whenever possible.

"I can remember an infant in a community downtown that was brought in. I think they eventually decided the child had smothered… We knew it was going to be a coroner's case, and when the nurse called the coroner I actually asked if I could talk with the coroner… and the police, also [about the needs of the bereaved]… So the coroner said… as long as no one touches the body, as long as a policeman is in the room [that it was OK].

"We made a big circle around that infant and prayed. Now maybe that coroner's assistant (or whoever because it's not the coroner that actually comes out) sort of bent the rules to do that… Then again, it's only anecdotal, and it could be that the next time something like that happened, you know, talking to the coroner's assistant wouldn't do any good. It is very difficult with the guidelines and the rules."[39]

— SOCIAL WORKER, FOCUS GROUP PARTICIPANT, FRESNO

IV. Factors Affecting EOL Care for Immigrants

> *"The truth is that terminally ill patients do not represent a health priority in this country. There are other programs that have historically preoccupied (governments more) from an epidemiological point of view, such as pediatric attention, infection diseases, and also cardiovascular problems. In consequence, there is big hole in terms of initiatives to support projects directed towards palliative care patients. In general, palliative care programs have emerged in Mexico as pain clinic projects. This means, that palliative care has become an extension of the pain clinic and this has its pros and cons [On the one hand, the already existent infrastructure has been used, but palliative care projects have been satellites without their own specific power]. Few places have a sector designated only for palliative care to look after exclusively this type of patients. There is only one place in Guadalajara that has received adequate governmental support; that is the Palia Institute that cares for terminally ill patients within the public sector. In the rest of the country, [palliative care programs] are inserted within other projects and the governmental support is not very evident so far".*[40]
>
> — INTERVIEW TRANSCRIPTION
> EDITED BY DR. ARGELIA LARA (9-29-04)

Use of Health Services

Recent studies on medical costs for foreign-born adults in Los Angeles County reported that immigrants—and undocumented immigrants in particular—use fewer health services than U.S.-born or resident citizens, and thus account for a smaller proportion of public spending on health care than previously thought.[41–43] Critics suggest that these studies underestimate the problem of immigrant health costs.[44, 45] Nonetheless, the salient issue for palliative or EOL care needs is not the bottom-line costs of immigrant care, but rather the conditions that influence the patterns of care utilization associated with these costs. For example, Latino immigrants in California have low rates of measurable health care utilization. Given high poverty rates among this group, these patterns may reflect lower expectations regarding the availability or benefits of health care. There are no reliable estimates regarding patterns of use of alternative (i.e., folk) medicine.

Access to Insurance and Other Public Benefits

A study on the need for universal health insurance reported that greater than 50 percent of uninsured adults in Alameda County are immigrants.[46] Sixty-eight percent of undocumented Latinos in Fresno and 84 percent in Los Angeles were uninsured, compared to 35 percent of Latinos nationally and 19 percent of all persons nationally.[47] Newly arrived immigrants and those who have not been in the United States long are mostly uninsured and less likely to be insured compared with the U.S.-born population or long stay immigrants.[48–50]

Consequently, immigrants may have lower rates of regular health care usage and use fewer preventive services than U.S.-born citizens.[51, 52] Having adequate access to care is undermined by a range of factors besides lack of insurance.[53] These include poverty, language and other cultural barriers, not understanding or having no knowledge of available programs, and fear of disclosure of undocumented status. The longer an immigrant has resided in the United States, the less effect these factors have on rates of insurance: the more integrated immigrants become in society, including increased English proficiency, the better able they are to understand the process for accessing public benefits. In addition, many older immigrants in California arrived before 1980 (two-thirds of the state's immigrant seniors) and may have become eligible for Social Security and other public benefits.[54]

Persons who are not U.S. citizens and who are not considered qualified immigrants (such as Legal Permanent Residents, refugees, and persons with asylum status) are not eligible for most federal and state health care benefits. However, they do have access to emergency care or limited preventive services (such as immunizations) that protect the public health. In California, in addition to emergency care, immigrants are also eligible for Medi-Cal long term care services and for limited cancer treatment under state breast and cervical cancer programs. They are not eligible for the Medi-Cal Hospice Benefit or for In-Home Supportive Services. These services may, however, be provided under some county health gap provisions or through charitable care in private sectors.

Despite availability of limited benefits, unqualified immigrants use fewer standard health care services than qualified non-native or native U.S. populations. This problem stems from pressures mediated through social and political institutions.[55] As such, there is a great need for advocacy to shape public policy for immigrant patients and their families. Unfortunately, identifying the needs of this population is hindered by access. The usual routes are limited when used to contact patients who may be ineligible for care. Access becomes even more difficult if patients have illegal status. Innovations in health insurance, such as cross-border programs operating under the Knox-Keene Act approved in 1998, or other alternatives, such as coverage provided under guest worker programs, may address some issues of access to care.[56]

Views Toward Palliative Care—an Example

There are at least three parties affected by and responsible for shaping trends and outcomes related to health needs of the immigrant: the receiving community (California or the United States); the immigrant and his/her family and community; and the originating nation or state.[57] With regard to palliative care, it is important to understand how it is viewed in the immigrant's home of origin. While palliative and hospice care have been embraced by European and English-speaking countries, they are less recognized in other countries for a variety of reasons. They may not be formally recognized as medical disciplines. Organizational resources and funding structures for hospice or palliative care may be limited or lacking altogether. The International Observatory on End-of-Life Care is a useful resource to better understand how palliative care is understood and practiced in developing countries. In an interview available on the Observatory's Web site (see pull quote on page 24), a palliative care consultant at the Instituto Nacional de la Nutricion in Mexico, DF, Dr. Argelia Lara, discussed the place of palliative care in the national health system in Mexico.[58]

Documented misperceptions and stigmas regarding palliative care in Mexico have included equating it with euthanasia.[59] Other cultural practices such as shielding terminal and other serious diagnoses from patients further complicate acceptance of palliative care by Mexicans. If immigrants from Mexico carry their expectations and norms regarding health care with them from their country of origin, the misperceptions and the lack of priority of palliative care within Mexico may account for lowered expectations for this type of care when they arrive in the United States.

V. Decision-Making

"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. She felt her role was to protect him, and so was trying to deal with that and provide him with good care."

"The daughter was a very high-powered businesswoman, very urban, and yet there were these values from her culture that kind of took over and it was kind of a conflict. She knew this wasn't how western society would do things, but she had to do it that way."

— FOCUS GROUP PARTICIPANT, LOS ANGELES

Racially, Ethnically, and Culturally Appropriate Care Planning

EOL care is also influenced by the degree of certainty that one is indeed dying and by the predictability of the timing of death.[60] These uncertainties can give rise to challenges in decision-making or become the source of ethical quandaries related to EOL care delivery that all persons may face, regardless of racial/ethnic or cultural background. The response from all parties involved—patients, families, primary providers, clergy, ethics consultants, specialists, and other health care personnel—may be influenced by their own values, beliefs, and worldviews. This may be the source of potential conflicts among groups that don't share similar values. Most tools of bioethics practices in U.S. health care settings, grounded in the worldview and value system of the dominant Western society, benefit patients who are English-speaking, educated, empowered, individual-minded, and desirous of autonomous control over their lives.[61] Conflicts often arise over disagreements or uncertainty about medical care when these practices are imposed on patients and families who do not fit that profile.

Most studies on and interventions for decision-making address situations that arise or are needed for terminal and, more recently, for chronic and frailty trajectory patterns. Few efforts have addressed decision-making needs for sudden trajectories.[62]

Case Study

A Latino male, appearing to be in his 20s, was found in the street severely beaten and comatose. He was brought by ambulance to the nearest emergency room, a large university hospital. He had no identification, and police had no information about who he was or what had happened. After emergency room physicians found a serious head injury, the patient was stabilized and admitted to the intensive care unit.

He remained in a coma and was considered a "friendless incompetent," a person without known family or friends to act as a surrogate decisionmaker. No guardian had been obtained for the patient when his condition began to deteriorate, presenting a quandary for the medical staff regarding decisions for medical interventions.

Although American bioethics theoretically considers withholding and withdrawing futile interventions morally equivalent, in practice, especially in emergency settings, persons delivering care in emergency or urgent situations may not see them as equal.[63] Emergency personnel are trained to act quickly to administer life-saving interventions and may need to make rapid decisions without the benefit of knowing patients' wishes or values. Without the benefit of time to deliberate or to determine patient preferences or beliefs, decisions to deny or withhold an intervention that may hasten death may feel more morally problematic than a decision to withdraw that care later on. Furthermore, working in resource-constrained environments with patients whose languages or values differ from one's own can compound the challenges in decision-making.

Advance Planning and Cultural Diversity

Advance planning is considered an important process through which patient values and preferences for care at the end of life can be made known to persons delivering health services in emergency rooms, hospitals, skilled nursing facilities, and at home. Like hospice and palliative care programs and services, efforts to increase advance care planning have been directed at persons for whom there may be predictable patterns of decline (older persons, those with chronic disease or cancer). However, given the patterns of abrupt death for all Californians, but particularly for younger multi-ethnic persons who are at risk for sudden, traumatic death, there is an advantage in knowing decision preferences (including identifying proxies or surrogates to make decisions) in advance before families face the overwhelming agony of having to make treatment decisions suddenly. However, it may be considered culturally inappropriate or undesirable among some communities and families to plan for or to discuss death in advance.

Case Study

A 69-year-old Vietnamese man arrived at a large urban emergency room in respiratory distress, possibly in need of emergency intubation. While reviewing his medical records, doctors discovered that he had been recently diagnosed with metastatic lung cancer and recommended for hospice.

The family had come with the patient; however, the only English-speaking member was a 9-year-old daughter, and the hospital translator would not be able to arrive at the ER for another 30 minutes.

The patient's condition worsened, and the doctors could not wait. Asking the daughter to translate, the attending physician asked if a do-not-resuscitate (DNR) status had been decided. The family, anxious and confused, said, "No." The daughter explained their belief that the patient had a "lung problem" and was only coming to the hospital to get treatment.

When the official translator from the hospital arrived, resuscitative efforts, short of intubation, had been going on for over thirty minutes. The medical staff, through the translator, attempted to discuss the previous recommendations for comfort care that had been made by the oncologist who had diagnosed his lung cancer. The patient was dying and a decision needed to be made regarding intubation. The wife replied that she could not make that decision. It had to be made by her husband's father or brother and neither would arrive for another hour.

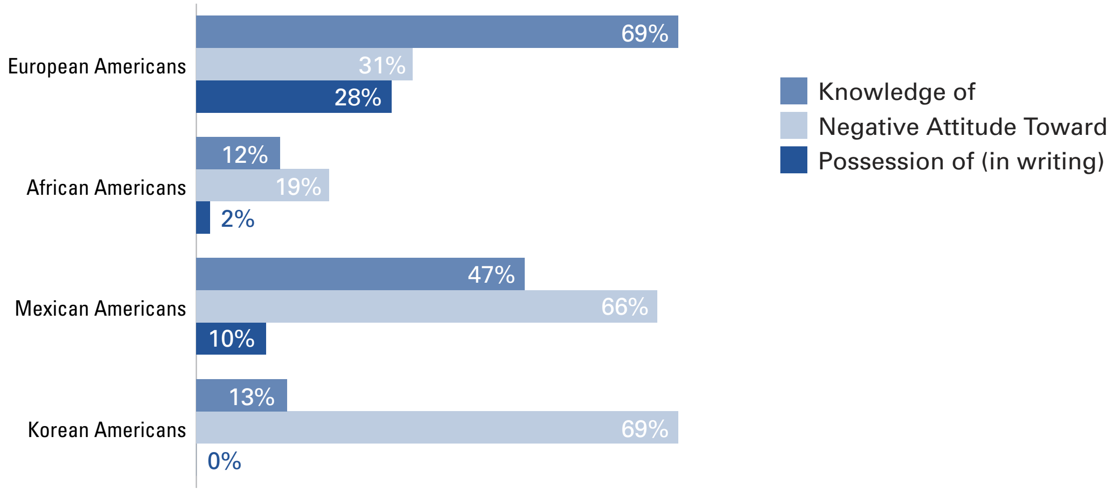
> *"Yes, I find that in the African American, as well as the Asian cultures, usually the family [doesn't want to] talk about putting it in writing. That family will come to an agreement if it comes to that point and the kids will decide what should be the best way to go. I think that basically, they are holding on to believing that the person will get better. They will not die. They will improve. But if they put it in writing, then that it is sort of like you hasten the death."*
>
> — FOCUS GROUP PARTICIPANT, LOS ANGELES

A study among European, Mexican, Korean, and African American elders conducted in Los Angeles in the mid-1990s showed variations in knowledge, attitudes toward, and completion of advance directives.[64] (See Figure 7.) European and Mexican Americans were most likely to know about advance directives. However, while African Americans were the least likely to know about them, once told about advance directives, they held the *least* negative attitude about them. Mexican and Korean Americans held the highest negative attitudes. Few in any group actually had completed an advance directive.

Respect for cultural diversity does not necessarily mean that one should abandon practices that can enhance care. The goals and intentions behind advance planning are worthwhile; however, studies and commentaries on its use in multi-ethnic populations have suggested that current implementation practices focusing on written documentation leave little room for compromise. As authors of the study on multi-ethnic seniors in Los Angeles concluded, "rather than focusing on increasing the completion rate of formal advance directives, we need to listen to the diverse voices of the communities we serve and then adapt our practices to fit their needs better."[65]

Culturally appropriate alternatives are also needed beyond translating educational materials and legal forms into multiple languages. Advance planning concepts also need to be interpreted into culturally appropriate and acceptable goals and strategies. Community-based approaches to advance planning

Figure 7. Advance Directives: Cultural Differences by Ethnicity



Murphy et al., Ethnicity and advance care directives.

that have their origins *within* the community and reflect the values and perspectives of particular ethno-cultural groups may be more successful in meeting the goals of advance planning.[66]

This project illustrates a more culturally synchronous way to promote the goals of advance directives, stressing the role of relationships valued in sociocentric cultures (in contrast to the role of autonomy and the value of cognitive-based strategies stressed in Euro-American society).

The Ethnic Health Institute: *Find a Friend*—A Model Project

In partnership with community organizations, the Ethnic Health Institute (EHI), a community outreach program of Alta Bates Summit Medical Center in Oakland, developed and implemented a replicable, culturally appropriate alternative to traditional advance care planning for African Americans. After studying what was known nationally about problems with advance directives among African Americans, project leaders conducted focus groups with members of the local African American community to determine alternative approaches that could meet the needs of both the community and health personnel.

Findings showed that in this community it was more appropriate to shift the emphasis away from expecting individuals to identify desired preferences in various EOL scenarios (with the idea that these preferences would then be written into a legal document). Alternatively, individuals should simply find a family member or trusted friend with whom they could entrust their values, in general. One of the slogans used in this project was the following: *"To love someone is to learn the song in his heart, and to sing it when he has forgotten it or can no longer sing it himself."*

The campaign became, *"Find your friend and then tell them what is important to you."* The focus was on clarifying values through *real* conversations about the individual's life, not about hypothetical future scenarios related to death. Project leaders adapted questions from the Values History Form developed at the Institute for Public Health Law at the University of Mexico School of Law and provided them as guides for recommended conversations.

EHI recruited African American physicians, clergy, and community (lay) persons, trained them to implement this work in the community, and then held several events to promote the project to wider audiences. Their goal has been to increase the number of proxies who might be better prepared to make informed decisions should the need arise.

VI. Pain and Symptom Management Issues

Ethno-Cultural Issues

Quality palliative EOL care requires aggressively addressing pain and symptom control. The landmark SUPPORT investigation (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) pointed to the failure of providers and the health care system in general to insure that patients would not suffer serious pain in their last days of life.[67, 68]

The psychological, spiritual, or existential meanings given to pain and suffering, its forms of expression, and acceptable approaches to its amelioration are, among other things, culturally mediated factors. In addition, there are interethnic differences in the metabolism and pharmacodynamics of drugs used in palliative medicine. Studies showing that minority patients routinely receive inadequate analgesia, including palliative treatment for cancer-related pain, highlight the need for both cultural sensitivity and competence in the areas of palliative and EOL care.

> *"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. They had never experienced anything that bad. 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."*
>
> —FOCUS GROUP PARTICIPANT, LOS ANGELES

Physician Education

Missed Opportunity: AB 487 and Racial/Ethnic Disparities

On October 4, 2001, California signed into law AB 487, the Pain Management and the Appropriate Care and Treatment of the Terminally Ill bill that requires California-licensed physicians to complete 12 units of continuing medical education (CME) in the subject of pain management and palliative care. The requirement is time limited: physicians licensed before 2002 are given until December 31, 2006 to complete this *one-time* requirement; physicians licensed in or after 2002 are mandated to complete the 12 units within four years or by their second license renewal date.

Background

The bill was originally introduced by former Assemblymember Dion Aroner, who two years earlier had unsuccessfully introduced California's Death with Dignity Act (AB 1592) that would legalize physician-assisted suicide. Among the advocates against AB 1592 were coalitions of medical and hospice organizations and groups representing ethnic communities and the poor, who were concerned that the bill would not address more pressing EOL care needs, primarily the lack of adequate knowledge among medical providers of documented race/ethnic-based disparities in pain management.

In June 2001, an Alameda county court awarded $1.5 million to the family of William Bergman, an elderly cancer patient who subsequently died, but who had experienced extreme suffering and agony as a result of his primary physician's failure to adequately treat his cancer pain. The physician was judged to be in violation of the California laws against elder abuse. Lawyers for the doctors argued that their client had not received adequate education on pain management in medical school or in subsequent training.[69] This case brought the issue of provider training in EOL care to the attention of lawmakers and AB 487 was introduced with the intention of preventing future cases.

AB 487 has been heralded as "a very extraordinary step…to address what is clearly an enormous problem."[70] It has also been called a model for other states to follow. It may be a novel and laudable effort to improve quality palliative care and pain management in general, but the state has failed to show leadership in addressing racial and ethnic disparities in EOL care. The authors examined the curricula offered in courses approved for credit toward the AB 487 requirement to determine the percent of ethno-cultural content. As the requirement can be satisfied through any hospital or organization nationally that offers accredited CME units, it was not possible to analyze the entire universe of courses. However, all courses advertised by the Medical Board of California, as well as courses offered through the University of California system, were examined. The authors also included a convenience sample of CME courses offered by private vendors.

What's missing? Few courses included any content on critical ethno-cultural factors that are associated with improved or worsened outcomes for seriously ill or dying patients. Given the documented racial and ethnic disparities in providing adequate treatment for pain, this was sadly a missed opportunity for addressing the palliative care needs for multi-ethnic patients and families.

In addition, there has been little to no oversight regarding the quality of courses and content that meet the requirements of AB 487. The California Medical Board reported that there is no oversight organization that manages the content or quality of CME courses. A spokesperson stated that as long as the course is offered by an accredited body and includes the topic of pain management, palliative care, or end of life, as indicated in the course objectives, it would meet the AB 487 criteria. The Institute for Medical Quality (IMQ) has been designated as California's intrastate accrediting agency by the nationally recognized accrediting agency for continuing medical education, the Accreditation Council for Continuing Medical Education. IMQ, on behalf of the California Medical Association (CMA), accredits California-based hospitals, ambulatory care clinics, specialty societies, health plans, and other health care organizations on a voluntary basis to offer Category 1 continuing medical education credit. Physicians who attend courses offered by IMQ/CMA accredited providers meet the Medical Board of California's Division of Licensure requirements for physician licensure and receive credits towards the American Medical Association's Physician's Recognition Award and the California Medical Association's Certification in Continuing Medical Education. A representative of IMQ/CMA stated that accredited providers are granted autonomy to create their own CME programs. Like the California Medical

Board, IMQ/CMA provides no direct oversight or regulation for meeting the AB 487 criteria.

Second chances? The lack of accountability for addressing ethno-cultural aspects of pain and palliative care may or may not be addressed by new legislation passed in 2005: the Cultural and Linguistic Competency for Doctors bill (AB 1195), beginning in 2006, requires all CME programs to contain a cultural competency component. This legislation may address the concern of inadequate education in ethno-cultural aspects of pain management and EOL care if the state continues to mandate provider education in pain and palliative care beyond the 2006 deadline. Otherwise, it may not, given the finding that community non-hospice or palliative care physicians would not voluntarily obtain continuing education in topics related to death or end of life.

Pharmacies

> *"I think in the very poor communities, there is an issue about access to meds. They may get the prescription from the doctor, but then they go in their community to get morphine and some of the pharmacies don't carry it. Maybe there is a financial issue, too, some of these drugs are quite expensive."*
>
> —FOCUS GROUP PARTICIPANT, LOS ANGELES

Undertreatment of pain is prevalent, particularly among the elderly, the poor, and patients who are racial and ethnic minorities. The reasons are complex and multifaceted. The Institute of Medicine (IOM) and National Academy of Sciences (NAS) assessed the inequities in delivery of health care services to minority populations in a report published in 2002 and verified that, remarkably, racial and ethnic minority patients were undertreated for all types of pain, across all health care settings.[71]

Racial/ethnic-related differences in health care utilization and access have been well documented and account, in part, for some of the inequities in pain management. Two key studies in New York City and Michigan suggested that limited availability of opioid-based pain medications in pharmacies located within minority communities may account for poor outcomes in pain management among ethnic populations. After surveying 30 percent of the pharmacies in New York City, investigators found that pharmacies in predominantly Latino and African American communities were less likely to stock sufficient quantities of opioid analgesics than those in non-Latino White neighborhoods.[72]

The Story Behind the NY Pharmacy Report

Dr. Morrison, a geriatrician at Mount Sinai School of Medicine in New York, noticed a disturbing pattern among his elderly cancer patients. Although he had appropriately prescribed proper medications, including strong narcotics or opioid drugs for their serious cancer-related pain, many of his Latino and African American patients would return for follow-up appointments stating that they had not been able to get their prescriptions filled for days at a time.

The consequence of this was that patients would spend hours to days in excruciating pain, although medicine that could relieve their suffering had been prescribed. When he inquired as to why they had delayed getting the prescriptions filled, the response was that they had gone to their neighborhood pharmacy but that time and again they were told, "We don't carry that."

As a result, he and his colleagues decided to investigate whether this was a random pattern, or one that showed systematic discrimination against minorities residing in predominantly ethnic neighborhoods. What they found was only 25 percent of pharmacies in Latino or African American neighborhoods had opioid supplies that were sufficient to treat patients in severe pain, as compared with 72 percent of pharmacies in predominantly White neighborhoods.

A more comprehensive investigation in Michigan provided similar results to the New York study, finding that pharmacies in non-White areas of Michigan were 52 times less likely than pharmacies in White areas to have sufficient opioid supply.[73] Further, corporate chain pharmacies were less likely than independent stores to have sufficient pain medication supplies. Differences on the basis of pharmacy type suggested variability in pharmacists' decision-making. Both of these studies illustrate important system-level barriers to accessing adequate pain medication in minority communities.

Access to Pain Medication in Neighborhood Pharmacies of Fresno

> *"I think I would say that probably [there is a problem with availability of pain medicines in pharmacies]."*
>
> *"If we have a patient that goes home and needs a medicine in a certain part of town… the pharmacy doesn't have that."*
>
> — FOCUS GROUP PARTICIPANT, FRESNO, CALIFORNIA

The authors were interested to find out if the data obtained in New York and Michigan were applicable to areas in California. The city of Fresno was studied, based on statements made during focus group sessions with non-physician health care providers there, suggesting that some of the minority patients were not sufficiently treated for pain, and that those patients may have had difficulty filling prescriptions for pain medications at their local pharmacies. Fresno was also selected as the study site because it is a racially diverse city, with approximately 40 percent White and 60 percent non-White residents, and was recently reported as the number one city for concentrated poverty in the United States (pre-Katrina New Orleans was second on that list). As there appeared to be clearly defined boundaries between poor and non-poor neighborhoods within Fresno city limits, the authors wondered whether or not there were differences in the prescription pain medication supply across the neighborhoods of Fresno. If differences did exist, they wanted to assess the reasons for such differences.

After obtaining IRB approval, the authors contacted all 84 independent and chain pharmacies in Fresno County. Although only 44 percent responded (n=37) to survey questions regarding availability of three tiers of pain medication (following the World Health Organization's Pain Ladder for treating mild to moderate to severe cancer pain), information on market and neighborhood attributes was available for all 84 pharmacies. This enabled the authors to impute data regarding adequacy of stocks for the missing pharmacies. (See Appendix C Sample Survey in the supplemental report.)

In summary, the authors found no statistical association between neighborhood ethnic composition and adequacy of stock among the 37 surveyed pharmacies. The number of pharmacies surveyed without adequate stocks of pain medications was 7 out of 37 (19 percent). They imputed that an additional 15 pharmacies (for a total of 26 percent) would be without adequate stock. (See Table 8.) The significant attribute for both collected and imputed data to predict adequacy of stocks was whether or not a pharmacy was a small independent store or part of a large chain. In this small study, corporate-based chain stores were *more likely* to carry sufficient stores of pain medications than independents. This finding was the opposite of the results from the study conducted in Michigan, which found that corporate pharmacies were less likely than independents to carry sufficient opioid analgesics.[74]

TABLE 8. Adequacy of Pain Medication Stock, Independent vs. Chain Pharmacies

PHARMACY TYPE	SURVEY RESULTS	IMPUTED RESULTS
Independent	23.33% (n = 7)	20.97% (n = 13)
Chain	76.67% (n = 23)	79.03% (n = 49)
	p = 0.01	p <0.001

Our qualitative data may explain this difference. Independent pharmacists in our sample were concerned about crimes related to burglaries and diversion. In 2004, a string of robberies of small pharmacies in Fresno may have dissuaded local pharmacies from stocking opioids and other Schedule II controlled substances.

> *"About a year and a half ago there were some pharmacies held up at gunpoint in Fresno because people were trying to steal Oxycontin. It got so bad that many pharmacies began putting signs in their store windows that said, "We don't carry Oxycontin."*
>
> — PHARMACIST, FRESNO, CALIFORNIA

Other reasons for the discrepancy between independents and chains may be related to costs. Pharmacists reported that the costs of drugs like Oxycontin and Fentanyl used to treat serious pain were high, while reimbursement through Medi-Cal or Medicare was low. Unlike chain stores that can shift stock among other stores within the chain, independents must absorb the costs of unused drugs that eventually expire.

> *"There are two major reasons why pharmacies might not stock pain meds: first, they are so expensive. It costs a lot for us to get them into the store. Second, reimbursement is really low on drugs like Oxycontin. For example, a prescription of Oxycontin may cost $2,300, and our reimbursement is $28. We have to absorb the rest of the cost. So it's a lose-lose situation."*
>
> *"I used to own two independent pharmacies before going bankrupt… Pharmacies, especially independents, may not be able to afford stocking a lot of pain medications... The new Medicare program makes everything more accessible to everybody but with less reimbursement and therefore less profitability for pharmacies, it's just too expensive."*
>
> — COMMENTS FROM INDEPENDENT PHARMACISTS

Lastly, pharmacist bias may have accounted for differences in stock at small pharmacies. In addition to fears of crime, some individuals held negative feelings based on stereotypes against certain ethnic groups.

"A young guy just walked out because I wouldn't fill his prescription. He had chains all over his clothes and more gold around his neck than I have in my entire house..."

"I don't think the issue is that the 'poor' people don't have access. I have no sympathy for the bleeding hearts who think that Medicaid is the best health care out there. These people don't pay anything for their Vicodin."

"We only serve the Asian population who don't need many pain killers. "

— COMMENTS FROM INDEPENDENT PHARMACISTS

The limits of this survey study include its small sample size. The universe of pharmacies in Fresno is only 84 stores. In addition, the reduced response rate was only 44 percent. Survey results based on missing data are subject to selection bias. The authors noted that respondents to the survey differed from non-respondents in that non-respondents were more likely to be chain pharmacies or stores located in minority neighborhoods. The authors' less successful attempts to get chain pharmacies to respond may have been related to difficulties getting permission from corporate officials to contact individual chain stores. As one pharmacist said, "There is a [corporate] policy not to release any info regarding on-hand quantity for controlled substances." To account for the missing data, results were imputed using identifiable attributes (publicly available market and neighborhood information) about each pharmacy. Although imputed data tends to overstate the accuracy of results, trends were found regarding adequacy of stocks in chain vs. independent status that persisted for both collected and imputed findings.

Conclusions

Although independent pharmacies in other California communities[75] and nationally[76, 77] have been shown to be more community-responsive than corporate-based chain stores, this trend may not be present in Fresno. A past history of pharmacy-related crimes and factors related to socioeconomics seems to have influenced differences in the availability of pain medications for Fresno residents. It would be useful to conduct a statewide investigation to identify other areas in California where availability might be problematic. Qualitative statements made by pharmacists in the Fresno study, however, raised other concerns regarding cultural sensitivity and competency.

In general, pharmacists are critical members of the health care team. They are gatekeepers for medications. They play a key role as liaisons between patients and their physicians, private and government insurers, and other players in the health care system. Most importantly, they provide front-line counseling on disease management as well as drug and non-drug therapies and devices.[78–82] Despite their important role, they are not held accountable in California to demonstrate cultural sensitivity or competency. Although pharmacists must complete 30 hours of continuing education every two years in order to renew their license to practice in the state, there is no equivalent mandate to AB 1995, the Cultural and Linguistic Competency bill for physicians, requiring continuing education programs for pharmacists to contain a cultural competency component.

VII. Culturally Appropriate Communication

"We mostly had problems with [using the] family for interpreting and obviously we don't know what they're interpreting… [and later on we] find out they're only interpreting half of what you're telling them. So now we tend to use the AT&T Line [over-the-phone translation], 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."

—FOCUS GROUP PARTICIPANT, FRESNO

Communication and Language

Ethnically diverse patient populations require a health care workforce that can provide culturally and linguistically appropriate services such as those recommended by the U.S. Department of Health and Human Services Office of Minority Health.[83] Obvious communication barriers occur when patients and providers do not share the same language or when a patient speaks a dialect.

In our observational study on interactions with EOL health care among low-income seriously ill and dying African American patients and families, the authors found instances where inadequate communication resulted from a patient's use of African American Vernacular English.[84] Many times the doctors did not understand what the patient was saying but did not seek assistance in having their exchange "translated." In cases similar to this, although each party may not fully perceive what is being said, the need for translation may not be apparent.

Varying populations differ in preferences for what information is conveyed and how that information is best delivered. Yet health care providers from culturally discordant backgrounds may lack guidance and skills on appropriate cultural and linguistic communication regarding EOL issues.[85, 86]

Trust and Trustworthiness in EOL Care

The experience of many health care providers is that trust, or rather, mistrust, among most ethnic populations is a common and serious barrier to effective care and communication.[87–91] But trust and mistrust are not simplistic, solitary concepts, and it may not be helpful to place the problem of lack of trust solely onto certain groups or individuals from these groups. Rather, these concepts represent complex processes that develop in relationships and in response to events. Trust may result from trustworthiness or perceived trustworthiness; therefore both sides of the relationship—the one who trusts and the one who is trusted—bear some responsibility for the outcome of interactions. The authors consider trust or mistrust in the context of medical encounters as referring to at least three distinct conceptual frameworks that characterize interactions between patients and providers.[92–94] These include: (1) **entrusting** the fiduciary relationship—trust that the provider or institution will look out for the patient's best interest; (2) **confidence in competence**—trust in provider skills and knowledge; and (3) perception of provider or institution's **interpersonal trustworthiness**—trust in the humanistic, altruistic motives evidenced by acts of empathy, credibility, or reliability. Mistrust can be defined similarly: the perceived lack of any of these attributes could engender mistrust that the patient's interest is at heart, that providers may be incompetent, or that they are uncaring or unreliable. Distinguishing various dimensions of trust or mistrust provides a useful framework for action: without a clear understanding of what is implied by either trust or mistrust, it is difficult to identify what can be done by whom for its cultivation.

Case Study[95]

Despite his young age, a 29-year-old African American man had several chronic life-threatening illnesses. He was on dialysis for kidney failure and had previously suffered two strokes. He generally received his primary care at one of the elite hospitals in the Bay Area by arrangement through his mother, a dialysis nurse. He had been arrested for marijuana possession and immediately, after being put in jail, began to vomit blood. He was initially taken to the prison infirmary, but was ultimately transferred to the nearest county hospital as his condition worsened. He was admitted to that facility where, over the next two days, his condition stabilized. During this period, he agreed to participate in a study being conducted at that hospital to observe interactions among seriously ill (dying and potentially dying) African American patients and health care providers. During an interview for the study, he was asked, "Do you trust doctors?" Rather than responding with a simple yes or no, his answers reflected the complexity of issues that need to be considered regarding trust and trustworthiness in health care.

> *"The [doctors] in jail, whew, they ain't no good. Their knowledge is very limited and it just ain't no place to be if you're sick."*
>
> *"Now the [private] hospitals, …of course if you're able to pick and choose where and who you want… the doctors I've worked with have been good. They've been really good… I mean, y'know, I'm still alive and I'm healthy."*
>
> *"This [county] hospital right here...it ain't one of the best I've seen… It needs some work. I've been in better… [but] the doctor [who cared for me in the county hospital], now he was pretty good. He was all right. He was a doctor and a caring individual at the same time. He spoke to me, gave me information, made me feel I wasn't going to die."*
>
> —PARTICIPANT IN STANFORD STUDY ON DYING

In the case example, the young man based his attitudes of trust on his confidence (or lack thereof) in the competence of providers, distinguishing, for example, between the doctors in jail, who he saw as incompetent, and the private doctors at the elite institution where he gets his primary care. On the other hand, his trust stance toward the care he received at the county hospital was influenced by his perception of being cared for interpersonally.

Mistrust based on the perception of conflicting interest is illustrated by a story told in one of our provider focus groups where a family felt that the hospital was less interested in the care of the patient and perhaps more concerned with the cost of his care.

Case Study

A Fresno health care provider tells of an elderly Hmong gentleman who came in for a fairly routine surgical procedure. He was encouraged to become ambulatory soon after surgery. During his recovery, he developed unexpected complications and needed to be transferred to the intensive care unit, ultimately needing to go on a respirator. The family became extremely distrusting of the hospital and medical providers, feeling that the reason why he was having complications was due to the rush to get him up and out of the hospital too soon.

Cultivating trust requires that all members of the health care delivery system examine and shift the focus of change onto their own trustworthiness:

- The patients' and families' interest should be prioritized over any competing ones. It is unethical to deliberate over costs when making treatment decisions at the bedside. This does not mean that providers should ignore their responsibility as stewards of limited health care resources. However, decisions on how to allocate resources should occur at system levels that include mindfulness of what is in the best interest of all patients.
- Regarding trust as confidence in competence, it is imperative to cultivate a community of providers at every level of health care who are skilled and knowledgeable in EOL and palliative care.
- Patients and families are more likely to feel cared about when approached in a manner that conveys humanistic concerns, including compassion, empathy, and honesty. This may require providers to honestly examine negative attitudes that they may hold implicitly and explicitly toward certain populations and to eliminate behaviors that may be deemed discriminatory.

Although California is a multicultural state, not everyone is comfortable acknowledging or appreciating and valuing these differences. Statements made by providers working in hospitals, nursing homes, and hospices highlight this finding:

> *"When I walk in to discuss end-of-life issues with my own culture there is such a… comfort level. When I go into another culture, I don't have that same comfort level I have within my own culture."*
>
> *"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. 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."*
>
> —COMMENTS FROM FOCUS GROUP PARTICIPANTS, LOS ANGELES

The 2002 IOM report on disparities in health care cited bias and stereotyping by providers toward racial and ethnic groups as a potential contributor to disparities in health outcomes.[96] In our Stanford observational study on interactions with EOL health care providers among low-income seriously ill and dying African American patients and families, the authors found that miscommunication and mistreatment of patients by providers was not likely the result of overt, conscious, or intentional acts of racism by the providers, but rather appeared to result from burnout.[97] Tremendous burdens were placed on the public health facility the authors studied, including serious service reductions that, in turn, overwhelmed the workload of otherwise dedicated health care workers. This finding is consistent with the IOM report citing implicit bias—that which is not a part of an individual's conscious awareness—as a source of discriminatory or biased acts that may surface when individuals are exposed to stressful situations.

Preparing a workforce to provide equitable, competent, and culturally and linguistically appropriate EOL care will require training models that address a range of critical issues. A good resource is the ACCESS curriculum, an innovative comprehensive EOL training program developed in San Francisco.

RESOURCE FOR CULTURALLY APPROPRIATE EOL CARE TRAINING

ACCESS: The Visions Model for Training in Culturally Appropriate EOL Care

ACCESS to EOL Care is a community training organization dedicated to improving the quality and accessibility of culturally appropriate EOL care for underserved communities. The organization was formed in San Francisco in 1997 by a group of experienced hospice nurses, social workers, and administrators who expressed concern that certain communities of people were not being adequately served at the end of their lives. ACCESS provides education about death, dying, and grieving through seven interactive educational modules presented from a multicultural, holistic perspective.

The ACCESS curriculum includes modules on:

- Frameworks for Multicultural End-of-Life Care (the Visions model)
- Symptom Management from a Multicultural Perspective
- Bioethics and Multiculturalism at the End of Life
- Honoring Spiritual Diversity in EOL Care
- Grief and Bereavement in a Multicultural Setting
- Caring for the Health Care Providers
- An Organizational Response to Meet the Needs of a Diverse Clientele

What is unique about ACCESS? It presents basic concepts needed for competency in EOL care in the VISIONS framework of multiculturalism. The ACCESS program is administered through VISIONS Inc., a nonprofit enterprise that has over 20 years of experience in supporting health service organizations, communities, and individuals in the development and maintenance of a multicultural perspective. The unique, research-based VISIONS training model helps overcome barriers to communication, relationship-building, and organizational development caused by cultural misunderstandings and apprehensions. It does not simply provide information, but fosters empowerment for individuals and organizations to make meaningful and longstanding change by helping participants develop strategies for education, advocacy, and support around issues of organizational transformation. It helps organizations and individuals create environments where differences are recognized, understood, appreciated, and leveraged to achieve greater productivity, and where all can perform to their full potential.

VIII. Effect of Immigration on EOL Caregiving

More than a quarter of California's nurses are foreign-educated, compared to only 5 percent nationally.

Immigration patterns affect overall demographic population shifts in unique ways. Some demographers suggest that the twin factors of the "graying of America" along with increases in numbers from immigrant populations will have an additive, aggravating effect, thus increasing burdens on limited health resources; others suggest that the effects will be complementary.[98] The latter argue that immigrants, who are generally younger and of working-age, will contribute additional resources such as taxes and other Social Security benefits to be paid into Medicare and other public programs that will benefit the elderly. In addition, these workers will increase the ranks of the health care workforce, including home health and long term caregivers, who will serve the needs of aging Americans.[99–102]

Increasingly Immigrant Workforce

While immigration has extensively diversified California's patient population, it has also diversified the state's health care labor force. The effect of immigration on the health care workforce may be most apparent in the nursing profession. Although foreign-educated nurses are practicing in all fifty states, California has the highest percentage of practicing registered nurses (26 percent) who are foreign-educated. (Florida, the state reporting the next greatest percentage of foreign-educated RNs, has less than 10 percent).[103] Overall, nurses who received their basic nursing education outside of the United States constitute about 5 percent of the U.S. nursing labor force, and the proportion of newly licensed RNs who are foreign-educated has been on the rise since 1998, exceeding 14 percent in 2003.[104] The Philippines is the largest supplier of registered and practical nurses in the United States, with 50 percent of foreign-educated nurses receiving their nursing education in the Philippines. Other countries serving as major sources of nurses include Canada, United Kingdom, Nigeria, Ireland, India, Hong Kong, Jamaica, Israel, and South Korea.[105] The percentage of foreign-born nurses emigrating from various African countries is also on the rise. In 2000, 17 percent of foreign-born nurses practicing in long term care settings who had been in the United States for 10 years or less came from African nations, as did 22 percent of nurse's aides.[106] In addition, the U.S. Census estimates that 30 percent of low-skilled home care workers in the United States are immigrants, excluding undocumented immigrants caring for people in private homes.[107] Workers trained in countries where palliative care and hospice is not available or not a priority may lack appreciation of or skills and competencies in this field.

Factors Fueling Immigrant Workforce

A complex combination of factors both in the United States and abroad are contributing to the changing demographics of the health care labor force in this country. American-born women, especially White women, are pursuing care-giving professions at lower rates than in the past. Between 1994 and 2002, the number of native-born nurses in the United States who were age 35 or younger decreased from approximately 490,000 to 380,000.[108] Turnover rates for health care workers have been reported as high as 50 percent in some of the nation's long term care settings. Several studies report issues of low morale and job satisfaction, which may be fueling such high turnover rates.[109, 110] In one study, nurses working in nursing homes expressed the lowest levels of job satisfaction among all medical settings, with only 65 percent expressing satisfaction.[111] Low wages, limited opportunities for professional growth and advancement, and poor working conditions are among the reasons women in developed countries are increasingly choosing careers other than health care. This trend has created shortages in health care workers and has subsequently opened up new job opportunities for immigrant populations. Like most immigrants in general, foreign health care workers come to the United States in the hopes of improving their quality of life and increasing educational opportunities for their children. Many skilled health care workers also choose to leave their native countries due to inadequate health care infrastructures, technologies, and limited opportunities for further training and career advancement.

Language Issues

One national survey of patients receiving EOL care revealed that patients place great importance on having a comfortable and trusting relationship with their physicians and nurses, and they value the ability to have open communication about death and dying with their health care providers.[112] Such sentiments should be the priority in considering assimilation training of immigrant health care workers entering the fields of EOL and palliative care. As increasing numbers of foreign health care workers arrive from abroad, health care facilities must ensure that the needs of both patients and staff are recognized and respected. Providing quality EOL care in an increasingly diverse setting will involve embracing the cultural differences and perspectives of patients and staff alike. In a state as racially and ethnically diverse as California, an equally diverse health care workforce may be part of the solution to improving access and communication, subsequently mitigating disparities in patient satisfaction and quality of care.

Communication skills are key to the successful assimilation of foreign health care workers into the nation's health care system. The effect that the linguistic skills of immigrant health care workers may have on their ability to provide quality EOL and palliative care is a multidimensional issue. Language barriers may limit the deep and meaningful communications that serve as the foundations of hospice and palliative care.[113] While limited English proficiency may negatively affect patient care and hinder communication with patients, staff, and family members, foreign language skills may also be a highly desirable asset in caring for an increasingly diverse patient population. According to the 2004 National Sample Survey of Registered Nurses, nearly 70 percent of foreign-educated RNs speak at least one language other than English, most often Filipino (48 percent of foreign-educated RNs). About 4 percent of foreign-educated nurses speak Spanish, and almost equal numbers speak French or an Asian language other than Filipino.[114]

A survey by the National Council of State Boards of Nursing found that newly licensed foreign-educated nurses were slightly more likely to have difficulties comprehending English-speaking clients or staff than were newly licensed nurses educated in the United States, but they were far less likely to have such problems when dealing with non-English-speaking clients or staff members.[115] In one study of patient and family experiences with hospice care, respondents for whom English was a second language emphasized the importance of hospices staffing caregivers who spoke their ethnic languages.[116] About 20 percent of California's general population self-reported limited English proficiency in 2000, with the top three foreign languages spoken in California being Spanish, Chinese (all dialects), and Tagalog.[117] Thus, the assimilation of bilingual health care workers, immigrants and non-immigrants alike, into California's health care system, may actually serve to improve communication barriers and narrow disparities in access to quality care.

Although foreign-educated RNs must demonstrate English proficiency as part of the credentialing process through the Commission on Graduates of Foreign Nursing Schools (CGFNS), such certification processes do not necessarily ensure English language competency at the level necessary in a medical setting. Language differences in terms of medical terminology, medication names, and abbreviations may serve as major communication barriers.[118] According to the CGFNS, many migrant nurses also identify face-to-face and telephone conversations as difficult. Difficulties in accurately communicating patients' conditions or changes in their conditions could potentially delay appropriate care or cause injury. Legislative efforts to bypass the language skills assessment requirements by the CGFNS in order to expedite foreign nurse recruitment may have a harmful effect on the delivery of care if medical errors occur as a result of miscommunication.[119]

Another key issue related to language competency in EOL care settings is the fact that foreign nurse's aides and other unlicensed health care workers are not subject to the same certification regulations and English proficiency evaluations as foreign nurses and other skilled health professionals. Some health care facilities offer immigrants with limited English skills positions requiring minimal contact with patients, such as housekeeping and kitchen services. These workers are often able to advance into different positions as their English skills improve, but not all facilities take such careful measures.[120] Based on U.S. Census data, about 12 percent of nurse's aides in long term care settings reported that they could not speak English or that they had limited English skills.[121] This may negatively affect patient interactions and the subsequent quality of care received since most of caregiving time in long term care facilities (60 percent) is provided by nurse's aides.[122] Health care workers with foreign accents may also have communication difficulties, regardless of their level of English fluency, and may face additional alienation and stigmatization in medical settings.[123] Some patients have reported feeling left out or ignored under circumstances where two caregivers are speaking a foreign language to one another while providing care.[124] Communication barriers may frustrate the health care workers themselves, as well as other staff members, but language issues may also affect patient perceptions of the care they are receiving. McElmurry et al. assert that "when patients have difficulty understanding a care provider, their trust or satisfaction with the care provided will be affected, thus creating undue dissatisfaction with nursing care."[125]

Discrimination

An unfortunate outcome of the growing immigrant health care workforce is discrimination and racism in the workplace, which may have a detrimental effect on job performance and satisfaction. One study exploring the experiences of Asian Indian female nurses who arrived in the United States after completing their nursing training in India describes various instances of racism from colleagues and supervisors.[126] Immigrant health care workers may also experience discrimination, based on their foreign status, from patients and administrators. In one American nursing home in which over half the staff is composed of immigrants, the director of human resources reports that hostility is rare, but patients may make derogatory comments or refuse assistance from an aide of another race. In addition, immigrant health care workers may face more subtle but equally devastating forms of discrimination, such as lower wages or reduced opportunities for career development and advancement.[127] To prevent such discrimination and racism, health care facility assimilation programs must thoughtfully integrate new nurses into the existing culture while educating existing employees about the far-reaching benefits of cultural diversity.[128]

Immigration Status Issues

While most skilled health care workers from foreign countries are eligible for special visas and often receive immigration assistance through recruiting agencies, unskilled health care workers have greater difficulties immigrating legally to the United States.[129] In May of 2005, President Bush signed legislation making 50,000 visas available to foreign nurses.[130] Similar immigration policies do not exist for unlicensed, unskilled workers such as nurse aides and medical assistants, although some national health care associations are lobbying for a new visa geared specifically to low-skilled and unlicensed workers, which would admit an additional 400,000 low-skilled workers into the United States annually.[131] Unskilled heath care workers do not typically arrive in the United States with the intention of working in the health care field. As a result, a greater proportion of these workers may be undocumented, further increasing their vulnerability to possible exploitation in the workplace.[132] The number of undocumented immigrants working as caregivers in licensed facilities, however, is thought to be low due to state regulations and heavy government monitoring of the field, including employee background checks.[133] The private home-care market may subsequently have a greater proportion of undocumented immigrant caregivers. To help protect undocumented health care workers from workplace exploitation, many service employee unions accept health care workers regardless of their immigration status.[134]

IX. Conclusion

"When I was going through the… Licensed Vocational Nurse program, they did a cultural [training] 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.'"

— FOCUS GROUP PARTICIPANT, FRESNO

ALTHOUGH THIS PROJECT FOR THE CALIFORNIA HealthCare Foundation had the goal of focusing on race, ethnicity, and culture in EOL care, one should acknowledge a potential risk of convenience: while respecting difference among California's various populations, there is always a risk of essentializing groups and stereotyping individuals.

By essentializing, that is to presume that all members of a group are the same, one may fail to acknowledge that individuals inhabit multiple socio-demographic identities simultaneously and that movement among these identities is fluid depending on need or the particularities of circumstances. It follows, then, that rarely is membership in a racial, ethnic, or cultural group the only factor influencing a particular patient and family's response and needs for EOL care.

Nonetheless, population trends and mortality patterns strongly suggest that attention needs to be paid to the complex phenomena of immigration as it relates to EOL care in California. Specifically, immigrants from Mexico, (particularly those who are undocumented and thus unqualified for benefits), who are young and important contributors to the workforce are at risk for dying young from trauma and accidents. While effective strategies and policy solutions for preventing these premature deaths are being devised, there still needs to be reliable access to and quality delivery of EOL care for patients and families through models of care appropriate to the trajectory of dying.

Efforts that have been undertaken in the last thirty years since the advent of hospice to improve the quality of life and health care for dying persons should continue to receive support, including increasing the number of hospitals and skilled nursing facilities that offer palliative care. While the hospice movement provides standards for what is needed for compassionate quality EOL care, certain tenets such as home-based care or structures for reimbursement may not necessarily be culturally appropriate nor meet the needs of certain segments of California's populations. Hospice is not the gold standard for all deaths.

While the goal of this report is to focus on recommendations to improve EOL care for the state's ethnically, racially, and culturally diverse populations, any efforts to improve care for all Californians will most likely have positive effects on the care of its multi-ethnic populations, as well. Conversely, efforts targeting care for diverse population groups — attending to and eliminating causes of disparities, creating and supporting culturally appropriate health delivery systems, improving processes of decision-making across cultures, addressing ethnocultural aspects of pain and symptom control, and generally improving communication and trustworthiness—will likely result in a care system that will benefit all of California's residents.

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