End-of-Life Care in California:
Racial and Ethnic Disparities

AHCJ Briefing
March 15, 2007
Outline

- Introduction
- New Program Area: Better Chronic Disease Care
- CHCF End-of-Life Focus
- Lake report
- Crawley report
- Wrap-Up
CHCF works to improve health care in California by promoting innovation in care and access to information so that people can get the care they need, when they need it, at a price they can afford.

- Founded: 1996, independent, nonpartisan philanthropy
- Location: Oakland, California
- Assets: Approx. $850 million
- Staff: 52
- Web site: www.chcf.org
CHCF New Program Areas

**Better Chronic Disease Care**
Improving the quality of chronic disease care; promoting appropriate care toward the end of life

**Innovations for the Underserved**
Lowering the cost of care for those in need

**Market & Policy Monitor**
Promoting transparency and accountability among policymakers and providers
Californians with One or More Chronic Conditions

- One (49%)
- Two (23%)
- Three (13%)
- Four (8%)
- Five or more (8%)
End-of-Life Care Issues

- Defining EOL care:
  - Usually at end stage of serious chronic condition, terminal illness
  - Common terms: palliative care, hospice care, advance directives.

- Challenges to providing good EOL care:
  - Cultural denial of aging and death in U.S.
  - Focus on aggressive treatment/cure
  - Financial incentives encourage intensive treatment

- Last six months of life:
  - Huge variation in costs across United States
  - More than 20% of Medicare FFS spending per patient
End of Life: A New CHCF Focus

- California is a critical place for EOL care:
  - Growing population over age 65
  - Ethnically diverse state
  - Poor communication among patients, families, clinicians

- CHCF Focus:
  - Care delivery innovations
  - Benefit design
  - Regulatory policy
  - Culturally appropriate services
CHCF Reports on EOL Issues

- Death and Dying in California (2006)
- Hospice In California: A Look at Cost and Quality (2006)
- Racial, Cultural, and Ethnic Factors Affecting End-of-Life Care (March 16, 2007)

Available at: www.chcf.org
EOL Differences Among Californians

Lake Research Partners 2006 survey and focus groups:

- Gap between patients’ wishes and care they actually experience
- Lack of communication between individuals and family members
- Significant multicultural and ethnic differences in preferences for EOL care
Racial and Ethnic Differences: Aggressive Treatment

- White: 69% Allow to die, 14% Always do everything, 14% It depends
- Latino: 39% Allow to die, 44% Always do everything, 14% It depends
- African American: 38% Allow to die, 44% Always do everything, 14% It depends
- Asian: 43% Allow to die, 28% Always do everything, 14% It depends
- Chinese-Speaking Chinese: 34% Allow to die, 39% Always do everything, 14% It depends
Racial and Ethnic Differences: Having Wishes in Writing

Very Important to Have Wishes in Writing
Actually Have Wishes in Writing

Chinese-Speaking Chinese: 34% (20%) - 43% (28%)
Asian: 43% (28%) - 68% (33%)
African American: 68% (33%) - 55% (20%)
Hispanic: 55% (20%) - 63% (47%)
White: 63% (47%) -
Racial and Ethnic Differences: Top Concerns (Lake Survey)

- Affordability is a top concern for Latinos, Asians, and Chinese-speaking Chinese
- Pain and discomfort is a top concern for whites
- Finding providers who respect your culture is a top concern for African Americans
Crawley Report: Key Findings

- Ethnically diverse populations use hospice care less than whites
  - Restrictions on curative care
  - Language barriers
  - Cultural barriers to acceptance of terminal conditions

- Undertreatment of pain prevalent among elderly, poor, and racial/ethnic minorities
  - Expansion of palliative care programs needed
  - Clinician training programs should include multi-cultural component
Key Findings

- Advance care planning (advance directives) isn’t as highly valued by some communities.

- Ethnic diversity requires a health care workforce that can provide culturally and linguistically appropriate services.

- Spread of culturally appropriate care models:
  - *Find a Friend Project* by the Alta Bates Summit Ethnic Health Institute focuses on sharing values in general with family or friends.
Key Findings

- Sudden deaths due to accidents and assaults are higher among young African Americans (11%), Native Americans (14%), and Latinos (16%), compared to Asian Americans (8%) and whites (7%)
  - Implications for ED services

- Clinicians lack skills to address culturally sensitive issues in end-of-life care
  - Few training opportunities for clinicians
Resources

- California HealthCare Foundation: www.chcf.org
- Center to Advance Palliative Care: www.getpalliativecare.org
- Caring Connections: www.caringinfo.org
- National Hospice and Palliative Care Organization: www.nhpco.org
- Growth House: www.growthhouse.org
- California Coalition for Compassionate Care: www.finalchoices.calhealth.org