

Cultural Awareness in End-of-Life Care



Goal



The goal of this presentation is to seek competence in cultural values and perspectives different than your own, to ensure that we provide culturally appropriate interactions with patients and their families.

Objectives

- Define awareness, sensitivity and competency
- Define the importance of cultural awareness and sensitivity at end-of-life
- Describe four American cultures:
 - African American
 - Asian American and five subcultures
 - Hispanic/Latino American
 - LGBTQ Community
- Describe for each, their:
 - Culture's basic values
 - Cultural/spiritual perspectives
 - End-of-life process

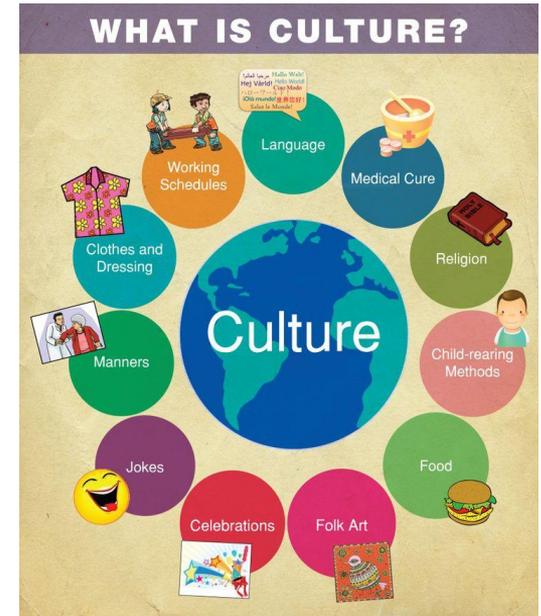
Diversity & Cultural Awareness



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‘Culture’ + ‘Curiosity’ = Culturocity®

A desire to learn about and interact with different cultures



Cultural Definitions

Awareness: developing sensitivity and understanding of another ethnic group

Internal changes in terms of attitude and values

Refers to openness and flexibility toward one another

Sensitivity: knowing that cultural differences and similarities exist, without assigning values

Cultural competence: behaviors, attitudes and policies that come together to work effectively in cross-cultural situations

Cultural Awareness

- **Developing sensitivity and understanding of another ethnic group**
Foundation of effective communication
- **Cultural sensitivity**
Recognizing other's values and perspectives
How we react to others in the world
- **Vital to decision-making**
Why we do things the way we do

Cultural Awareness

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Why we do things the way we do

“Misunderstandings arise when I use my meanings to make sense of your reality.”

Misinterpretations

Lack of awareness

My way is the only way

I know their way, but my way is better

Our own culture is not conscious to us

My way and their way

Look for cues – unspoken and spoken –
be present

Projected similarities

Assuming people are similar may lead us to act inappropriately

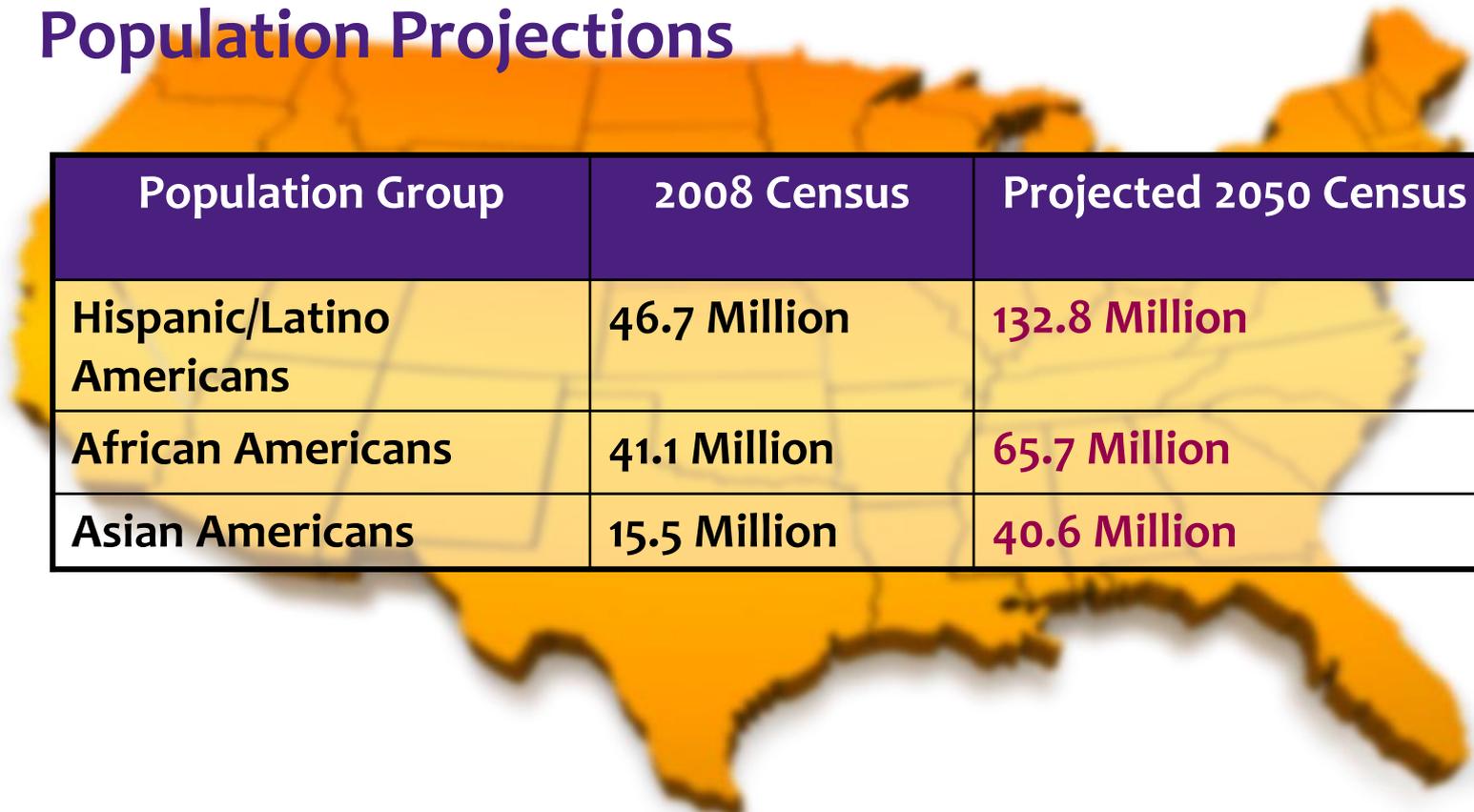


Embrace and Celebrate Diversity

- Admit you don't know
- Suspend judgments
- Use empathy
- Continually check your assumptions
- Become comfortable with ambiguity
- Celebrate diversity



Population Projections



Population Group	2008 Census	Projected 2050 Census
Hispanic/Latino Americans	46.7 Million	132.8 Million
African Americans	41.1 Million	65.7 Million
Asian Americans	15.5 Million	40.6 Million

Patients by Race / Ethnicity

Patient Race	2008	2007
Caucasian	81.9%	81.3%
Multiracial or Other Race	9.5%	7.8%
Black / African American	7.2%	9.0%
Asian, Hawaiian, or Other Pacific Islander	1.1%	1.6%

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Patient Ethnicity	2008	2007
Non-Hispanic or Latino origin	94.4%	94.9%
Hispanic or Latino origin	5.6%	5.1%

African American's Countries of Origin

Sub-Saharan Africa

Nigeria, Ghana, Ethiopia,
Eritrea, Egypt, Somalia



Caribbean Islands

Bahamas

Haiti

Latin America

Mexico

Panama

African Americans – Cultural Perspectives

Shared history – victims of the slave trade

Wide range of:

- Belief systems, traditions and practices

- Socioeconomic classes and educational levels

Distrust of medical establishment

- Healthcare disparities

- e.g. 1932 Tuskegee experiments - men with syphilis were intentionally untreated for 40 years



Care for loved ones at home

African Americans – Cultural Perspectives

Western Medicine accepted, along with alternate remedies:

Folk healers, spiritual elders

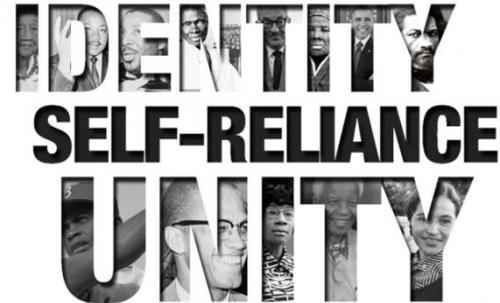
Home remedies, rituals, herbs

Always use direct eye contact

Address patient/family formally

Large extended families

May include non-blood ‘relatives’



African Americans – Spiritual Perspectives

Church is a vibrant part of the community

Embrace a broad range of religious beliefs

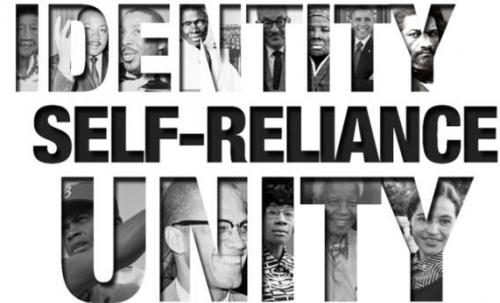
Protestant Christianity

Catholicism

Islam

Buddhism

May view hospice services as “giving up”



African Americans – Death And Dying

May feel conflicted

Aggressive treatment vs.
death as a ‘welcome friend’

Traditional ‘home-going’ (funeral) services
celebrate life

Services delayed to allow family to gather

Emotions are expressed openly at services

Attitudes towards cremation, autopsy and organ donation



Asian Americans



Asian American – Subcultures

Subculture

A group within a culture that has distinctive patterns of behavior and beliefs

We will look at Five subcultures

1. Chinese Americans
2. Japanese Americans
3. Korean Americans
4. Vietnamese Americans
5. Filipino Americans



Asian American – Countries of Origin

- Bangladesh
- Burma
- Cambodia
- *China*
- India
- Indonesia
- *Japan*
- *Korea*



- Laos
- Malaysia
- Pakistan
- The Philippines
- Sri Lanka
- Taiwan
- Thailand
- *Vietnam*

Largest Asian American population lives in New York and California

Asian American – Values

Importance of family

Hard work



Self-discipline

Respect for elders

Commitment to education

Asian American – Cultural Perspectives

- Prefers to care for elders at home
- Prefers to obtain help within the family
- May not readily seek out services
- Difficulties with language – especially elders
- Male hierarchy of authority
- Suffers in silence



Asian American – Cultural Perspectives



Guilt

Shame

Self-control

Saving face

Asian American – Spiritual Perspectives

Wide Spectrum:

Buddhism

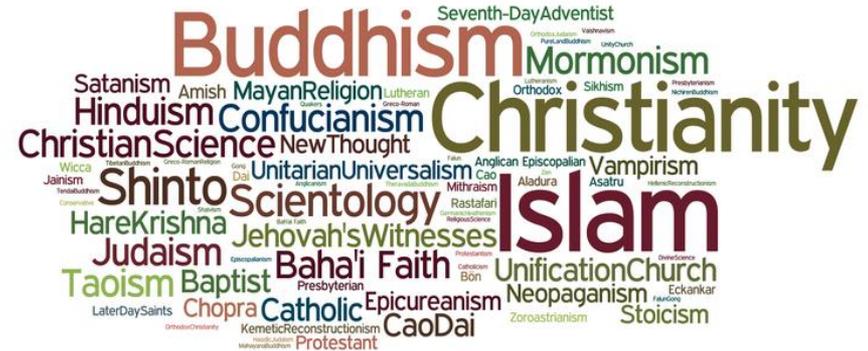
Christianity/Catholicism

Confucianism

Hinduism

Judaism

Islam
Shintoism
Taoism



Asian American – Death And Dying

Great respect for the body

Funeral planning

Shrines

Cremation

Generally object to autopsy and organ donation

Stoicism

Depression may result from internalized grief



Chinese American – Cultural Perspective



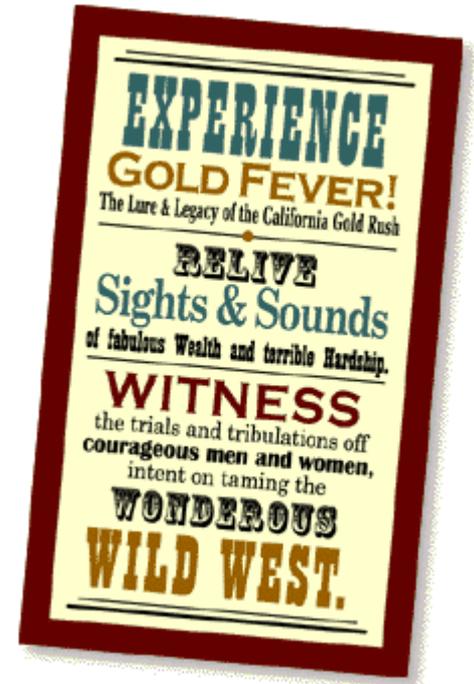
Chinese American – Cultural Perspective

First Asians to immigrate to the U.S. during the California Gold Rush

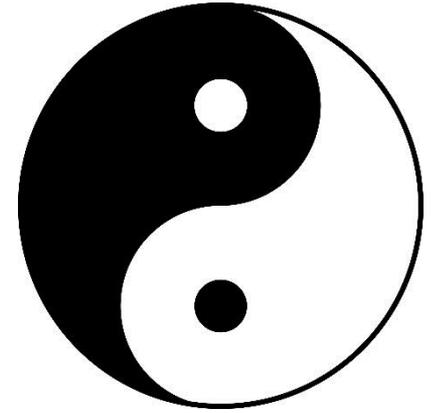
Largest Asian American culture in U.S.

Harmony of body, mind and spirit

Shy and modest



Chinese American – Cultural Perspective



- Use of family name important
- Yin and Yang
- Food to treat illness



Chinese American – Death And Dying

Family loyalty is paramount

Decision-making authority given to male family members

First the husband/father, then the eldest son

May not complain

Suffer in silence, may not verbalize pain

Dying at home

May bring bad luck,
however, spirit may get lost in the hospital



Chinese American – Death And Dying

Response to the subject of death:

- May not wish to discuss it

- May want to talk with their loved ones themselves

- May prefer patient not be told

Special cloths may be placed on body at time of death



Chinese American – Death And Dying



May prefer to bathe loved one

End-of-life rituals may include:

- Incense burning
- Special foods
- Good luck symbols
- Weeping/wailing at funeral



Japanese Americans



Japanese Americans



- Education highly prized
- Humble, courteous and thoughtful
- Social codes and manners

Japanese Americans – Cultural Perspectives



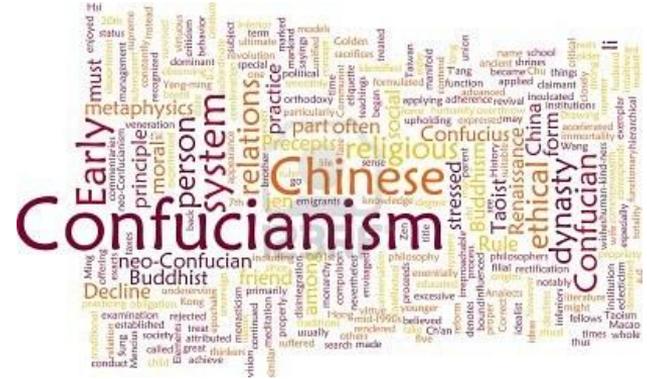
Foundation in Confucianism

- ✓ Filial Piety - a respect for parents and ancestors
- ✓ Devotion to family
- ✓ Honor – Shame - Duty



Japanese Americans – Death and Dying

- Parents should be cared for at home
- Open discussions approached with respect
- Funeral/ceremonies give high honor to the dead
- Open coffin is common
- Monetary gifts may be given to the family



Korean Americans



Korean Americans – Cultural Perspectives

- Assimilation & Integration
- High regard for family
- Indirect communication observed
- Stoicism
- Herbal, ancient remedies and acupuncture used at times



Korean Americans – Death And Dying



Reluctant to use hospice
Longevity is a blessing

Mourning style

Crying/wailing/chanting

May prefer to clean/bathe body

Incense burning

Praying

Cremation common

Vietnamese Americans



Vietnamese Americans – Cultural Perspectives



Family is paramount

“A drop of blood is better than an ocean of water”

Two sacred family obligations

Care for elderly parents and mourn them in death

Immigrants were refugees

Many suffer from PTSD

Uses little resources outside of family

Vietnamese Americans – Cultural Perspectives

May not seek outside resources

May experience PTSD

Greet with smile and quarter bow

Desires more distant personal space

Women do not usually shake hands

Indirect communication observed

Open expressions considered rude

Avoidance of eye contact

May hesitate to ask questions
or discuss death openly



Vietnamese Americans – Cultural Perspectives

Disease caused by imbalance of forces
Elders may not trust Western medicine
Denial or high tolerance of pain –
illness is their destiny

Tet – Highly coveted
Vietnamese New Year

January 19th – February 20th



Vietnamese Americans – Death And Dying



Mourning begins before death is imminent

During the death process:

- ❖ Strict silence is observed
- ❖ Entire family assembles around dying patient
- ❖ Eldest child records last words and suggests a name
- ❖ Ceremonial cleansing, body never left alone
- ❖ Rituals performed, special mourning clothing, altars
- ❖ Everyone is required to cover their heads



Filipino Americans



Filipino Americans – Cultural Perspective

- Families come first
 - many family members may have come to the US to help their families financially
- Having a large family is highly valued
- Respect is central value
- Very polite and shy
- Family often has a spokesperson



Filipino Americans – Cultural Perspective



Healthcare

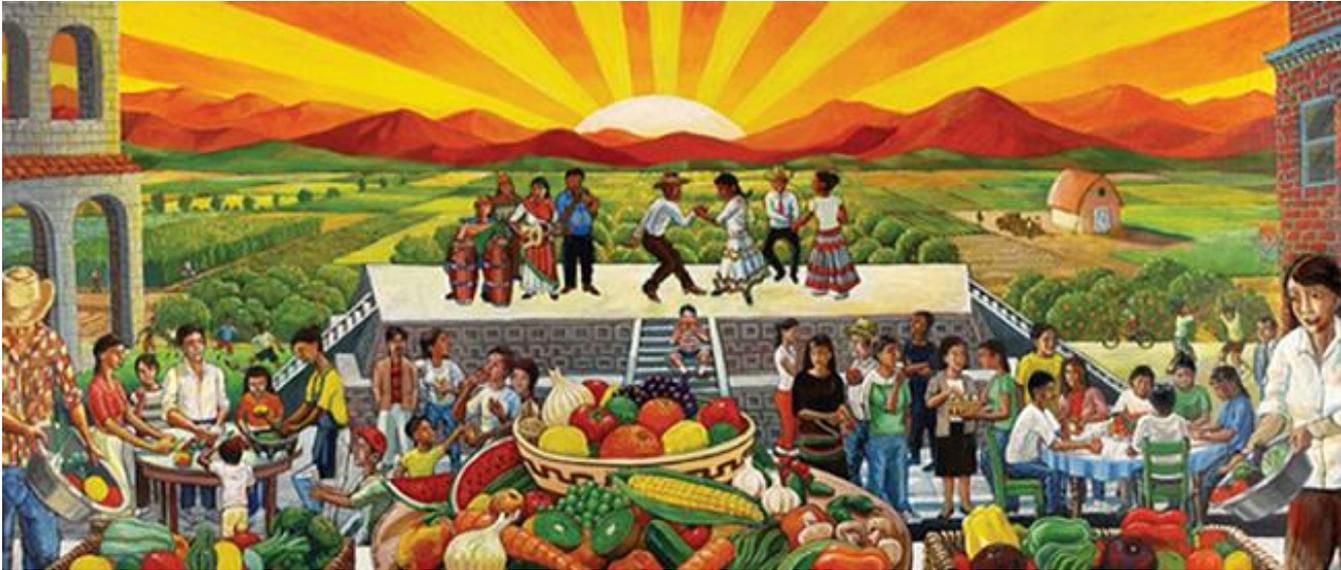
- Families prefer to take care of the elderly at home
- Traditional healing and modern medicine co-exist
- Patients tend to endure pain rather than to ask for medication
- Illness might be considered as punishment
- Consult family before presenting patient with terminal diagnosis

Filipino Americans – Death And Dying

- Largest Catholic population in Asia / Pacific Islanders
- For Catholics death rituals are very important
 - Sacrament of the Sick (formerly: last rites)
 - Blessing by a priest
 - Family gathers for prayer at the bedside
- Some families might want to ship body of loved one back to Philippines



Hispanic/Latino Americans



Hispanic/Latino Americans – Countries of Origin

Argentina

Belize

Bolivia

Chile

Colombia

Costa Rica

Cuba

Dominican Republic

Ecuador

El Salvador

Guatemala

Honduras

Mexico

Nicaragua

Panama

Paraguay

Peru

Puerto Rico

Spain

Uruguay

Venezuela



Hispanic/Latino Americans – Cultural Perspectives

Country of origin defines subculture, dialect

The family is paramount



Western medicine accepted

but may also observe:

- Folk remedies,
- Spiritual healers
- Curanderismo

Hispanic/Latino Americans – Cultural Perspectives

Cultural differences

Nodding of the head is done many times out of respect, and is not necessarily indicative of agreement or understanding

Comfortable social distance of Americans is about double that of Hispanics

Matriarchal family structure

Eldest daughter usually leads



Hispanic/Latino Americans – Cultural Perspectives

Spiritual affiliations:

Roman Catholic – Last rites performed

Protestant/Evangelical Christian

- Remaining at home is often the major concern
- May observe altars, religious symbols
- Low use of hospice



Hispanic/Latino Americans – Death And Dying



- Thoughts on talking about death:
Talking about death might make it happen
Talking about death is wishing it will happen
Belief that there's always room for a miracle
- Pre-planning funerals may be viewed as announcing death
- Elder Hispanics rarely attend bereavement groups
- Attitudes toward cremation, autopsy, and organ donation

Challenges for LGBTQ End of Life (EOL) Care



Challenges for LGBTQ EOL Care

‘We Made This Family’



<http://sdgIn.com/news/2016/08/02/elderly-lesbian-woman-abused-retirement-home-residents-being-gay-staff-ignores-pleas>

When Eleanor went into a nursing home to receive the care she needed in her final days, she was open about who she was as a lesbian.

“You still have time before you die to repent, change your ways and be saved,” a Certified Nursing Assistant (CNA) at the nursing home told her.

HuffPost Healthy Living, The Blog

Demographics / Population Estimates:

- 3.8% of Americans identify as lesbian, gay or bisexual
- One should not assume sexual orientation and gender identity are static over life course
- LGBT older adults in 93% of counties in US
 - 3 million over the age of 65
 - 7 million by 2030 over the age of 65



Mental Health Challenges for LGBTQ EOL Care



A GRANDFATHER has revealed he is gay after spending 90 years in the closet – despite knowing about his sexuality since he was five-years-old.

Fredricksen-Goldsen PhD – The Aging and Health Report: Disparities and Resilience among LGBT Older Adults. Seattle: Institute for Multigenerational Health 2011. NIH sponsored

- Coming out, internalized homophobia, stigmatization lead to higher risk for depression, suicide, risky behavior and substance use
- Loneliness and social isolation are contributors about 50%
- Suicide risk higher
 - 39% in The Aging Health Report cohort contemplated suicide
 - Highest in TG Older adults at 71%
 - Race/ethnicity differences
 - Highest depression, stress in Hispanic and Native American
 - Higher neglect in Hispanic and African Americans

Family Related Challenges for LGBTQ EOL Care

Social Networks



- Twice as likely to live alone compared to heterosexuals
- Four times more likely to be childless
- Do not gain the same health benefits as heterosexual couples
- Chosen family not biologic



Advance Directive Challenges for LGBTQ EOL Care

- 18% Health Care Proxy
- 12% Living Will
- Reasons cited for not completing
 - Not necessary now
 - Not aware of document
 - Not aware how to complete it
 - Hughs et al. 2015

LGBT persons often turn to "logical kin" during a medical crisis.



Remember to recognize your chosen family and appoint a decision-maker in your advance directive.

COALITIONCCC.ORG #PrideMonth #LGBT PrideMonth #HPM

COALITION FOR
COMPASSIONATE CARE
OF CALIFORNIA

- 42% Health Care Proxy
- 38% Living Will
- Much higher than general population as sample connected to LGBT Health and Social Services
 - Stein et al 2001

Managing Language Barriers



Provide an interpreter

- Avoid using family members as interpreter

- Be sensitive to dialects

Ensure you distinguish their country of origin

- Be very careful not to make **assumptions**

 - Example: Calling a person Chinese when they are Vietnamese or Korean

- Ask country of origin if necessary

Communicating by Telephone

Address person properly

Use correct title

Speak warmly/slowly

Don't be in a hurry

Practice name pronunciation

Efforts to speak their language are appreciated

Remember to smile

It reflects in your voice



In Summary

Be “gracious guests” in the homes
of our patients and families.

Please remember:

Listen more, speak less, **be present**

Ask open-ended questions, **be curious**

Do not impose your judgment, **be empathic**

Respond to how others view the world, **be understanding**

Presentation’s objectives met?

Questions ?



References

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National Hospice & Palliative Care Organization. NHPCO FY2008 National Summary of Hospice Care Washington, D.C., 2008.

THINKs on Diversity

i-net at Learning Resources → Program Training and Resources → Team Meeting → THINKs on Diversity → THINK Asian American

Quappe, Stephanie, Cantatore, Giovanna. What is Cultural Awareness Anyway? How Do I Build It?. Culturocity.com, 2007. www.culturocity.com

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