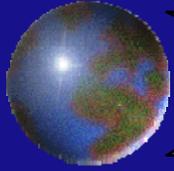


# ***Culture and Survivorship***

## ***Third Biennial Cancer Survivorship Research Conference, Cancer Survivorship: Embracing the Future***

October 4-5, 2006

Marjorie Kagawa-Singer, Ph.D MN, RN  
UCLA School of Public Health  
and  
Asian American Studies Department

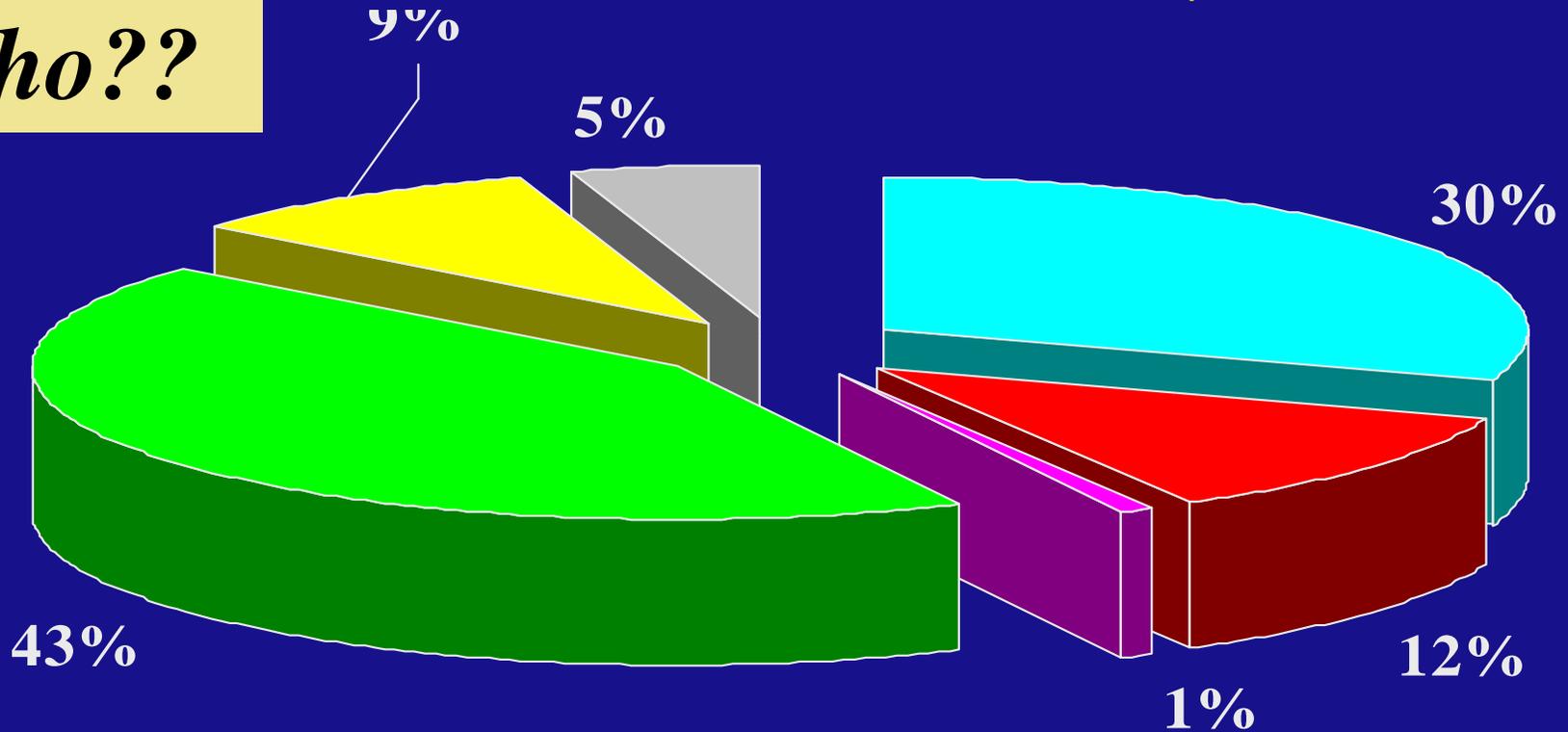


# Los Angeles Demographics

## 2000

Population = 9,519,338

**Who??**



Whites (Non-Hispanic)

Asian or Pacific Islander

American Indian & Alaska Native

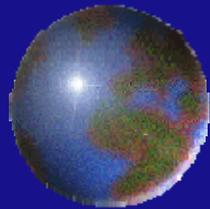
Hispanic

Black or African American

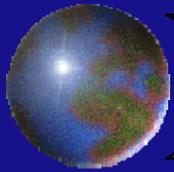
Two or More Races

**What do we know about survivorship among diverse populations?**





***Dearth of studies of the  
needs of Ethnic Minorities  
and Medically  
Underserved despite over  
35 years of work in the  
European-American  
population***



**🎗️ NCI Office of Cancer Survivorship 1991**

***“Cancer Survivorship Research  
Among Ethnic Minority and  
Medically Underserved  
Groups”*** *Aziz & Rowland, 2002 ONF (v29)*

**🎗️ 1966-2002: 65 articles**

**🎗️ Physiologic**

**🎗️ Patterns of care**

**🎗️ Psychosocial**

**🎗️ Quality of care**

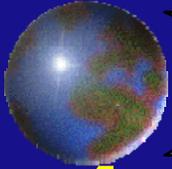
**🎗️ Health services**

# Survivorship, Support Groups, and Quality of Life Lit Search

<b>General Lit Search*</b>	
Survivorship	44,952
Support Groups	2,828
Quality of Life	2,398
<b>TOTAL</b>	<b>50,178</b>

<b>Ethnic Group</b>	<b># of Studies *</b>
African American	21
Amer Indians/ Alaska Native	2
Asian Americans	11
Latino/Hispanic	12
Pacific Islanders	
Native Hawaiians	1
American Samoans	2
<b>TOTAL</b>	<b>49</b>

Valdez, A., PubMed, search Oct, 2006



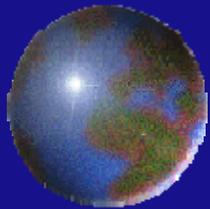
*And what evidence do we have on the survivorship experience for underserved populations at Each Stage of the Cancer Care Continuum ?*

**Cultural**

1. **Diagnosis**
2. **Treatment**
3. **Rehabilitation/Support**
4. **Palliative Care**
5. **End of Life Care**

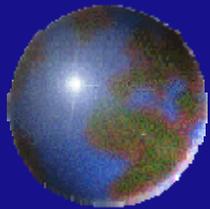
**Context**

# *General Findings in Review of the Literature (37 – 1995-2006)*

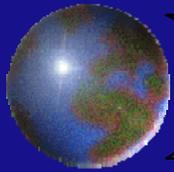


- **Samples:** primarily low income African American and Latinos
  - **Aggregation** of groups confound findings
  - **Age and gender** differences are significant and unstudied
  - Sources of **support** need to be differentiated from types of support
- (Bloom, 1995) (con't)

# *General Findings in Review of the Literature (37 – 1995-2006)*

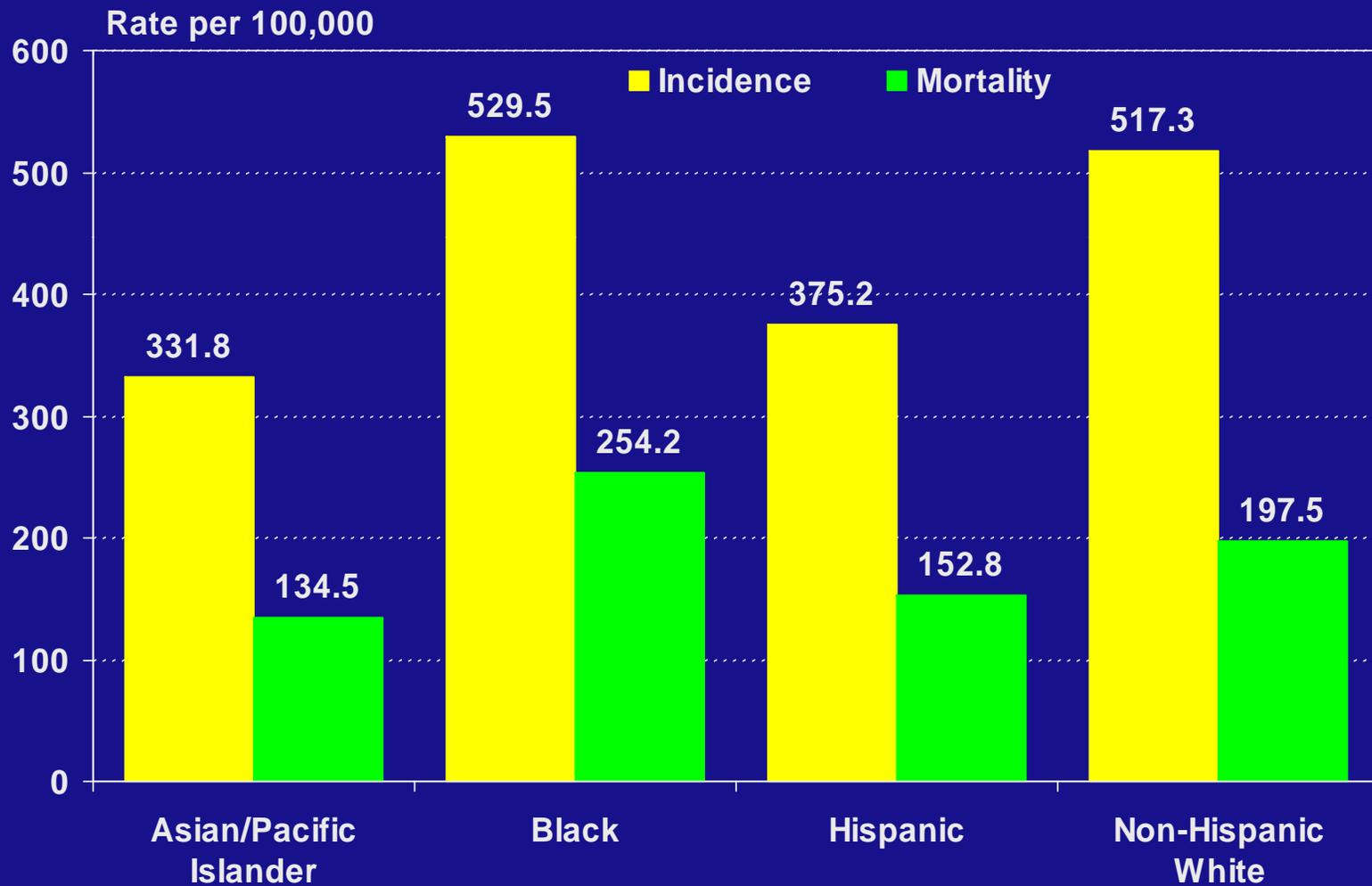


- Need for family focus and recognition  
**EVERYONE** has a culture (Gotay, 2000)
- **Spirituality** is fundamental strength in Latino and African American cultures
- Establish **cultural equivalence** of concepts such as “QOL” and “survivorship” and of measures themselves (Padilla & Kagawa Singer, 2004)
- **Services** unavailable, inaccessible or culturally incongruent

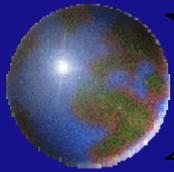


# All Cancers

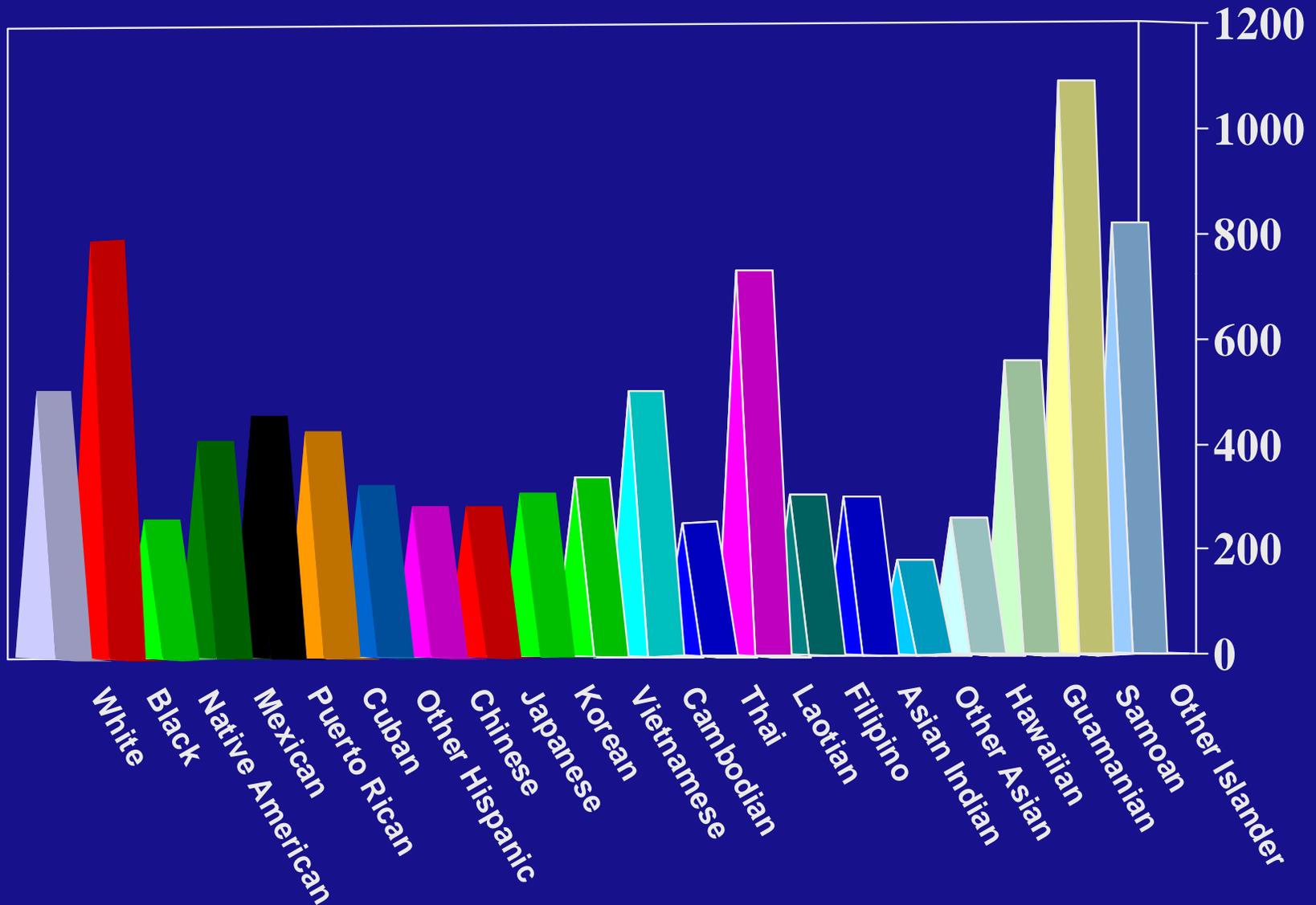
*Five-Year Average Annual Age-Adjusted Incidence and Mortality Rates per 100,000, California, 1997-2001*

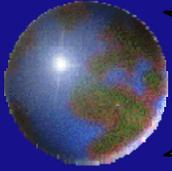


S. Kwong, 2004 – California  
Tumor Registry



# Age-Adjusted Death Rates Due to All Causes, California 1990



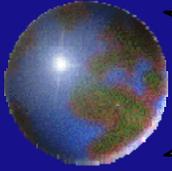


# ***Equal Cancer Treatment = Equal Cancer Outcomes***

- Sufficient studies for lung, breast , prostate to demonstrate race is not a biologic category
  - ❖ 21<sup>st</sup> Century – positive findings by ethnomedical research of genotypic polymorphisms
- UNequal treatment = UNequal survival

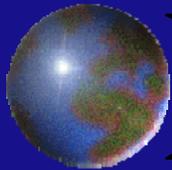


Brawley OW, Freeman HP. Race and outcomes: is this the end of the beginning for minority health research? *J Natl Cancer Inst* 91: 1908-9. 1999.



# Treatment

- 🔓 Timely –delivery of quality care
- 🔓 Standard of care
  - 🔓 Training of physicians/nurses
  - 🔓 Access to state of the art treatments
  - 🔓 Ability to tolerate side effects
    - 🔓 Supportive care, e.g., epoetin alpha, G-CSF, “Neupogen”
  - 🔓 Culturally Competent Care
- 🔓 Clinical trials



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# **Buy One, Get One Free!**

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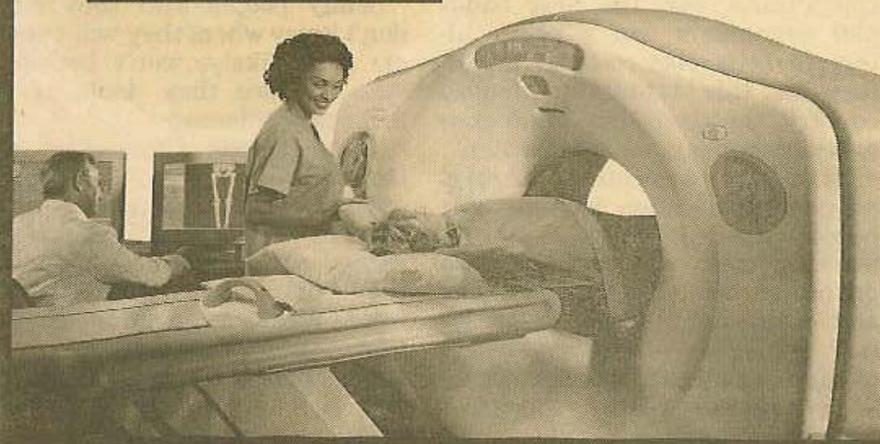
**(866) 848-2874**

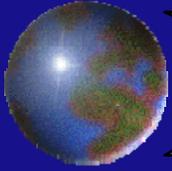
**(866) 848-CTSi**

**[www.ctscreening.com](http://www.ctscreening.com)**

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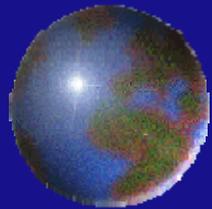




(McCaskill-Stevens, *J of Clin Onc*  
2005;23:5247-5254)

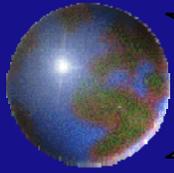
# ***Clinical trials***

- **NCI breast cancer treatment clinical trials 2002-2005**
  - 14% are minorities
    - ❖ 7%-8% African-American
    - ❖ 2%-4% Hispanics
- **Minority-Based Community Clinical Oncology Program 1995-2003**
  - ❖ 51%-67% minorities compared to
  - ❖ 23% other cooperative groups and affiliates
- **Breast Cancer Prevention Trial (BCPT) and STAR –**
  - ❖ Initially only 3% and 6% respectively
  - ❖ BCPT – 40,000 risk assessment forms/1600 Af – Am - 98 to randomization
  - ❖ STAR – 120,000/10,000 Af Am. - 291 to randomization



# *Palliative Care and End of Life Care*

-  Pain control
-  Psychosocial support
-  Spiritual support



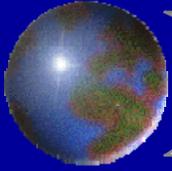
## *End of Life Care in Communities of Color*

- ? How do clinicians assure a “dignified” death if the death is premature because quality, state of the art evidence based treatments and interventions were not provided in a timely fashion - or at all? (Crawley, 2005)
- ? 50% of patients overall die in moderate to severe pain in the few days before death.
  - ↑ Diverse populations or the poor –
- ? 85% of hospice patients are white – 8%-10% Af Am, <2% Asian Americans – **Where do we die and how?**
- ? Prevailing pattern of NOT attending to ethnic differences in outcomes for palliative care studies



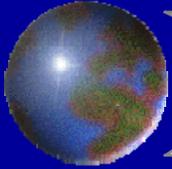
# Key Definitions

- ★ **Race** - scientific MYTH - assumed genotype based on phenotype
- ★ **Population Group** - population which has similar adaptive physiologic responses and cultural practices due to ecologic niche - e.g. sickle cell, G6-PD
- ★ **Culture** - system of beliefs, values, lifestyles, ecologic and technical resources and constraints
- ★ **Ethnicity** subcultural group within a power structure of a multicultural society & self identified group membership
- ★ **Racism** - assertion of power; ego fulfillment & racialization status at expense of others by **skin color** - color coded groups



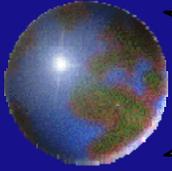
## *Culture affects:*

- Concepts of Health - and death
  - Mechanistic
  - Social
  - Metaphysical
- Pain experience
- Drug metabolism
  - Fast/slow - genetic polymorphisms
- Emotional responses -
  - Expressive
  - Stoic



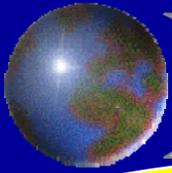
## *Culture affects:*

- 🌐 Decision making styles
  - 🌐 Concepts of autonomy
  - 🌐 Head of the household/clan/village elder or chief
- 🌐 Dependency expressions
  - 🌐 Gender roles
  - 🌐 Age
- 🌐 Social Support - who and what and when
  - 🌐 Concepts of "privacy"/individuality
- 🌐 Communication patterns -
  - 🌐 silence/non-verbal – weakness/strength



# *Health =*

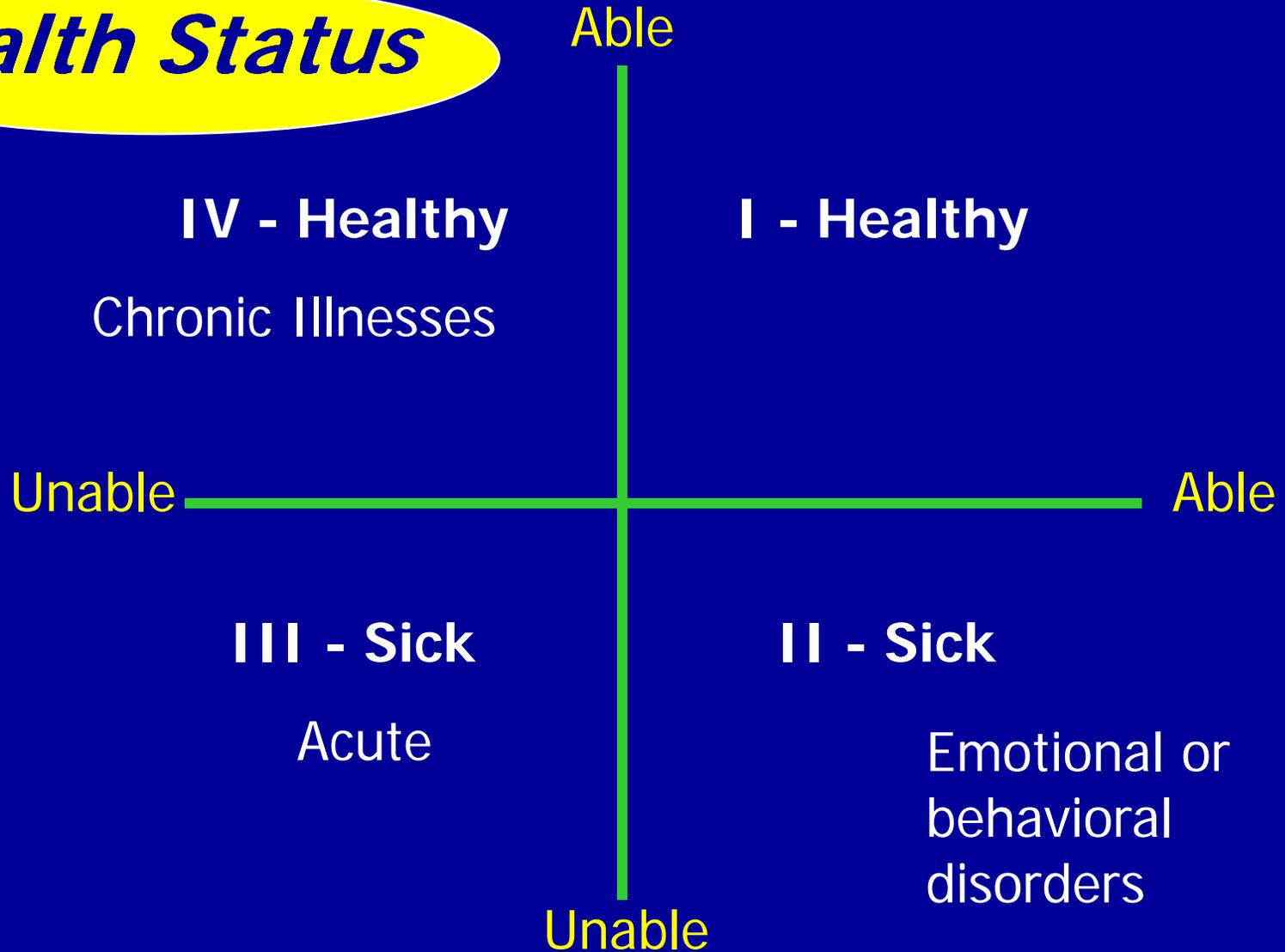
Ability to work towards life objectives and lead full and fulfilling lives as an essential part of one's social network

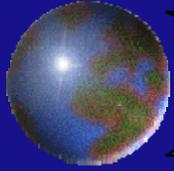


Social Function

**Health Status**

Physical Status



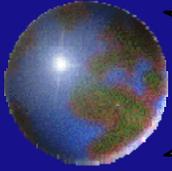


# PAIN PERCEPTION

Country	Phys.	Psych.	Interference
Vietnam	3.81	4.84	Low
Japan	3.73	4.64	Low
Taiwan	3.54	4.06	Low
Thailand	3.20	4.40	Low
Puerto Rico	3.06	4.80	Hi
USA	3.00	4.43	Hi

Davitz, et al, 1976 Scale 1-7 Vignettes

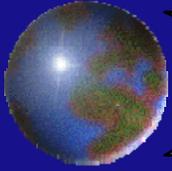




## *U.S.A. Values*

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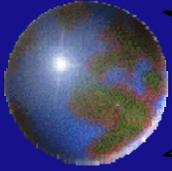
- Independence
- Self-reliance
- Autonomy
- Happiness



## *Values of Everyone Else*

---

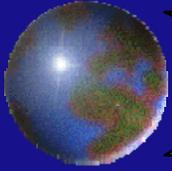
- Collectivism
- Interdependence
- Community



## *Values of Other Cultures Regarding Health*

---

- Individual life is not sacred
  - group welfare is foremost
- Decisions are made by group-consensus
- All life is suffering

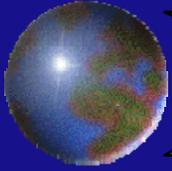


# *Culture*

---

**TOOL** which its members use to assure their:

- **survival**
- **well-being**
- **meaning and mechanisms** to make predictable and controllable the unpredictable and inevitable.

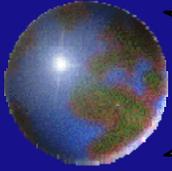


## ***2 Dimensions of Culture:***

- ❑ **Integrative** - those beliefs, behaviors and attitudes that one learns that provide a sense of integrity and belonging.
- ❑ **Functional** - prescriptions of behavior that define a good person in that world view





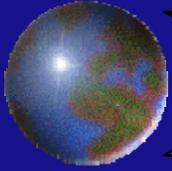


# ***Culture is comprised of:***

---

- Environment
- Economy
- Technology
- Religion/World-view
- Language
- Social Structure
- Beliefs and Values

Hammond, P., 1976,  
Diamond, J. 2004



# *Ethnic groups of color in the U.S.*

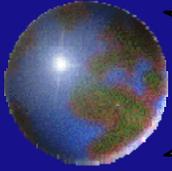
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- Behavior is influenced by:
  - Cultural Beliefs
  - Minority Status



American Beats Kwan for the Gold!  
1998 Olympics - US Women's Figure Skating

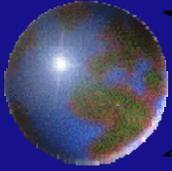




# *How does culture affect the science of survivorship studies?*

---

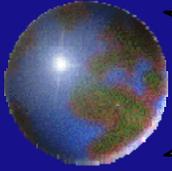
- Conceptualization
- Operationalization
- Cross-cultural equivalence of measures
- Relativity of validity
  - Internal?
  - External?



# *Study of Cultural Differences*

---

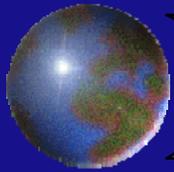
- Differential vulnerability
- Differential protection
- Differential CARE



# *Cultural & Linguistic Cross Cultural Skills*

---

- Affects quality of care
  - Patients do not follow/do not understand prescribed courses of treatment
  - Possibility of Misdiagnosis
- Required under Civil Rights Laws
  - Title VI of 1964 Civil Rights Act (Federal)
  - Dymally-Alatorre Bilingual Services Act (State)
- ✓ Language and cultural equivalence of survey and measures



Title VI of the Civil Rights Act of **1964** mandated that translation services be provided for all limited English speaking patients.

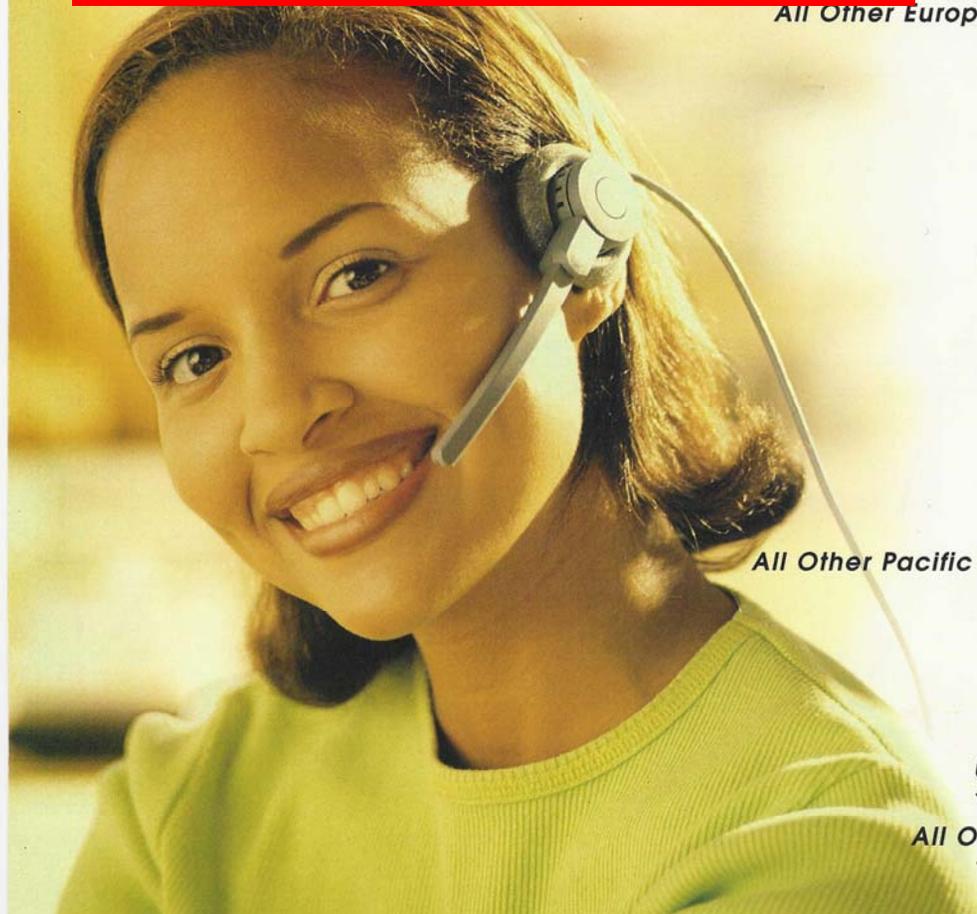
**2006** – yet to be accomplished in health care.

2003 OMH CLAS Standards

**Call Us** ...we speak your language

Wir sprechen Ihre Sprache! • Nous parlons votre langue! • ¡Y hablamos su idioma!  
日本語でお答えいたします。 我們能以您熟悉的語言與您交談！

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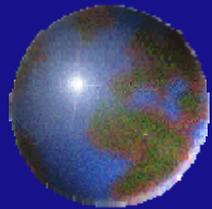
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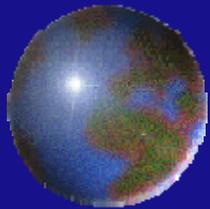


***What do we need to do  
from this point forward  
in addressing the needs  
of the underserved?***

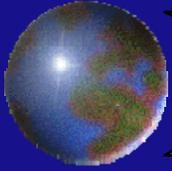
1. Change the culture of research
2. Change the culture of NCI



# *Research Designs*



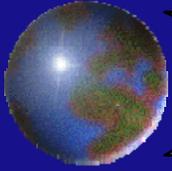
- Culturally valid theories and constructs
- Mixed methods using mixed paradigms ~
  - Deductive
  - Inductive



# *Metaphor of Cultural Responses*

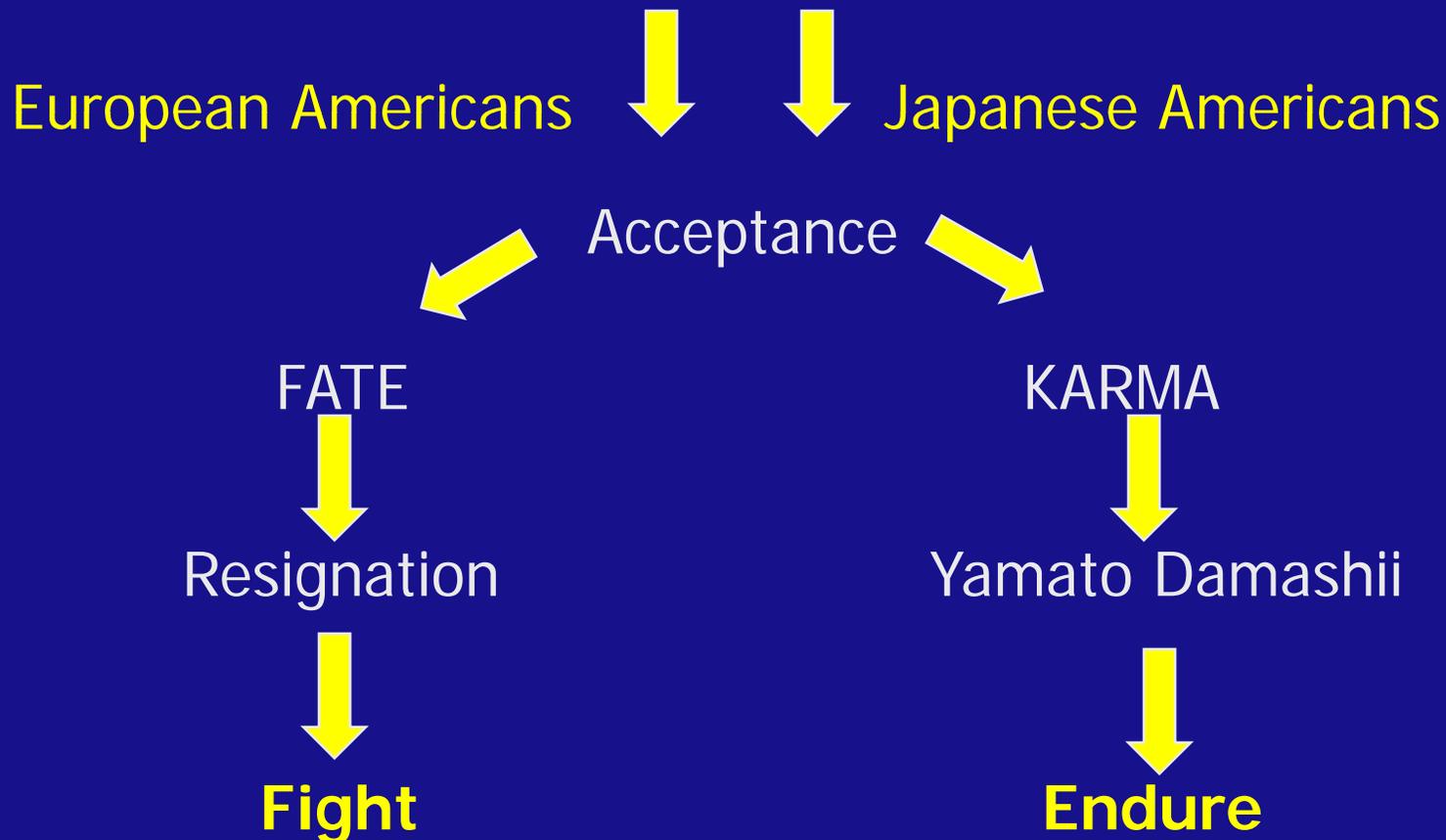
☐ Oak and ☐ Bamboo

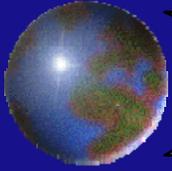




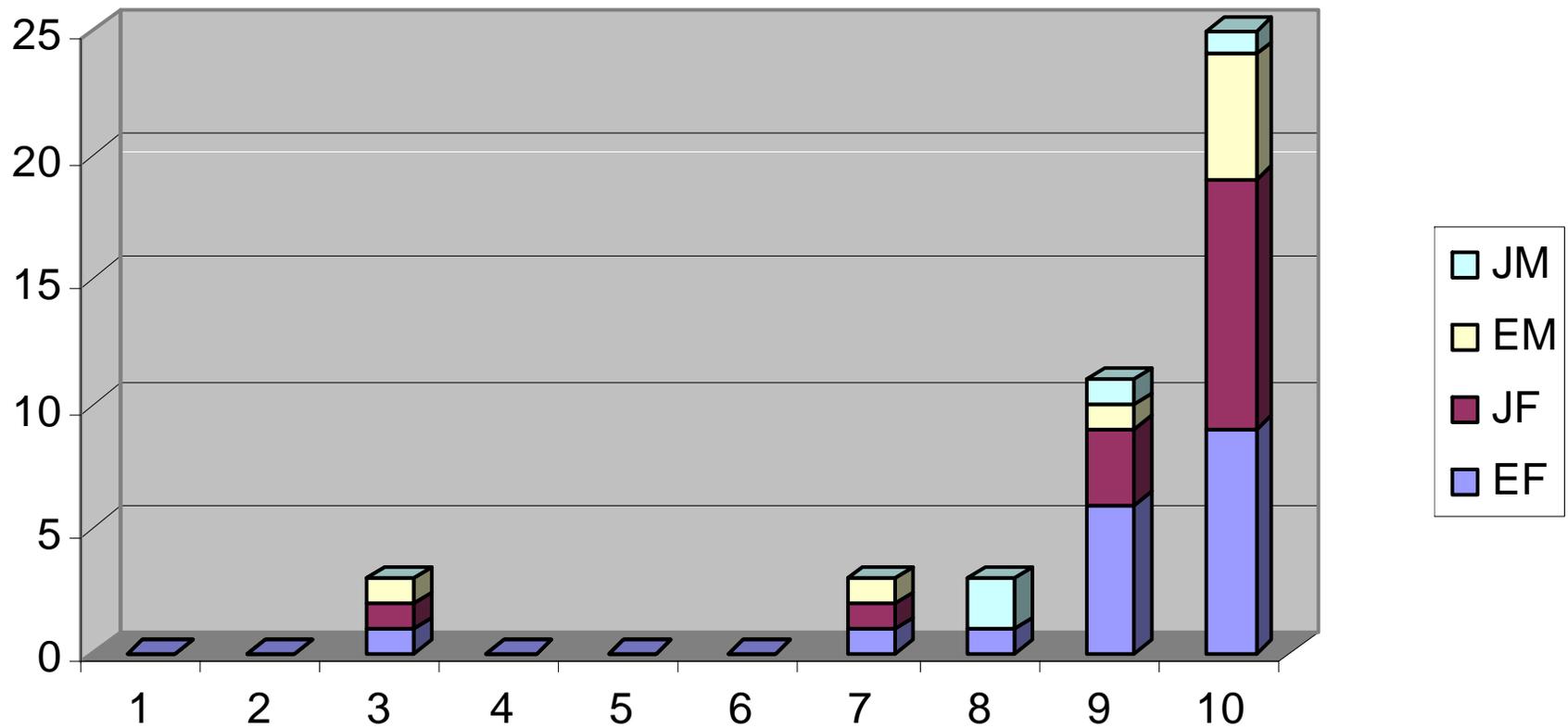
# Summary of Cultural Responses

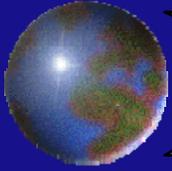
CANCER CRISIS





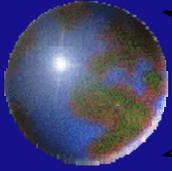
# Self-Esteem - Rosenberg by



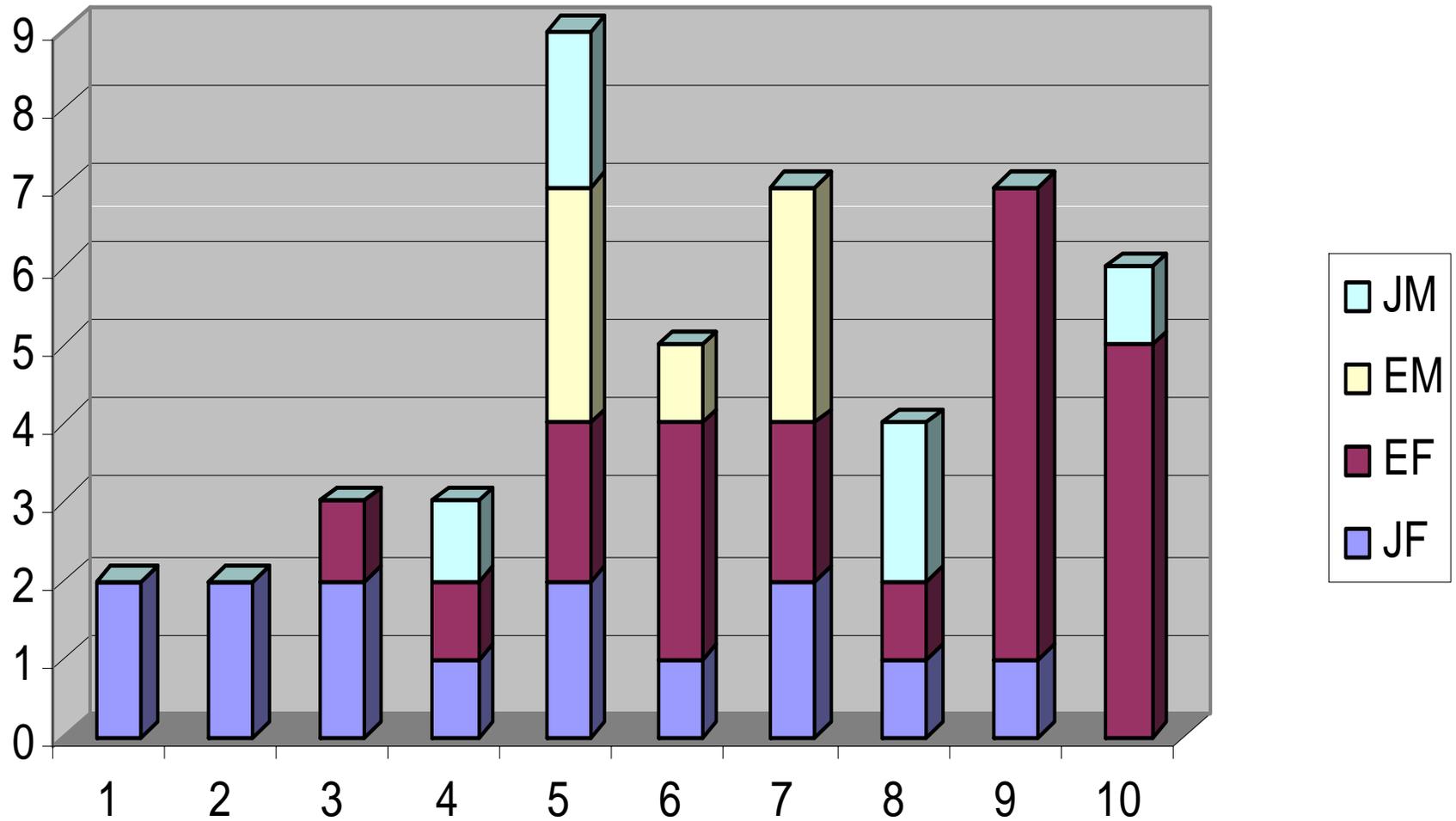


# *Ideal Qualities*

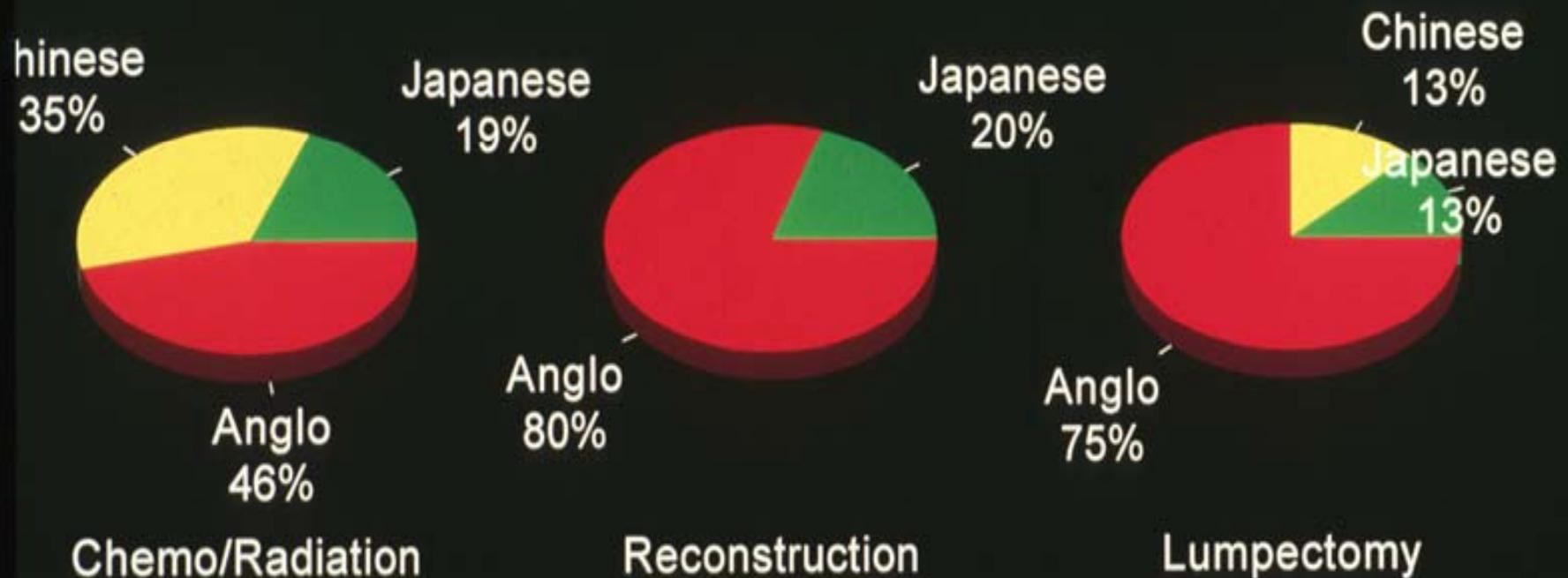
- Good self-esteem
  - Humble & No ego
- No complaining/  
Patience
- Compassionate
- Personable
- Understanding
- Intelligent
- Intelligent
- Kind/ Responsible
- "Together"
- Happiness
- Independent/  
Open-minded

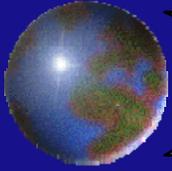


# Distribution of Self-Evaluation Scores



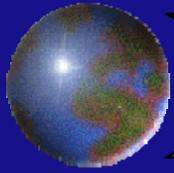
# Treatment by Ethnicity





## *Differences that make a difference ~*

<b>FUNCTION</b> (similar across sites)	<b>FORM</b> (tailored to community)
<i>Provide Optimal Treatment</i>	<i>Delivery Information/messenger</i>
<i>Provide effective support</i>	<i>Who, what, when, and to whom</i>
<i>Promote QOL</i>	<i>Domains and relative salience</i>
<i>Minimize discomfort of side effects</i>	<i>Meaning of suffering Communication styles</i>

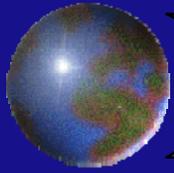


# *Relationship with Husbands of Chinese-, Japanese- & European-American Breast Cancer Survivors*

Kagawa-Singer and Wellisch, 2002 Psycho-Oncology

## **Theme 1: Vulnerability – h & w emotional dependency**

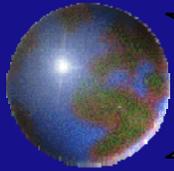
<b>Domain</b>	<b>Japanese-</b>	<b>Chinese-</b>	<b>Euro-American</b>
<b>A. Emotional Dependency</b>	Same for all three groups		
<b>B. Cultural permission for dependency</b>	No Self-sacrifice and nurturer		Yes
<b>C. Husband's mode of help-seeking</b>	Family of origin > wife	Silent	More expressive and > wife
<b>D. What husbands provide</b>	Same for all three: 1) pragmatic problem-solving – tangible, reassurance; 2) need for wife to remain in role of nurturer, emotional support		



## *Relationship with Husbands of Chinese-, Japanese- & European-American Breast Cancer Survivors*

### Theme 2: Nature of marital relationship

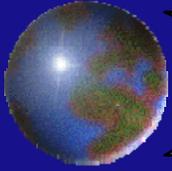
Domain	Japanese-	Chinese-	Euro-Americams
A. Mutual emotional give and take	<b>Same for all three groups</b>		
B. Harmony and Intimacy	Harmony rather than intimacy predominates		Intimacy predominates v. harmony
C. Communication	Non-Verbal – Inshin denshin in Japanese and Zhih Yi in Chinese		Direct and verbal communication is valued
D. Role expectations	Wife's role clearly differentiated as emotional nurturer and husband as source of security		Ability to be dependent on husband



## *Relationship with Husbands of Chinese-, Japanese- & European-American Breast Cancer Survivors*

### Theme 3: Sources of dissonance: Meeting needs

Domain	Japanese-	Chinese-	Euro-Americans
<b>A. Empathy</b>	Expectations of wives not met by husbands		
<b>B. Recognition of individuality</b>	Invalidation of individuality	"cut a little slack" but 'abandoned' to own resources	No time out from ongoing stress in relationship
<b>C. Perceived types of support from H</b>	Pragmatic problem-solving assistance and tangible aid – driving, housecleaning, also reassurance and calm		
<b>D. Sources of support for W</b>	Friends/co-workers (3)	Daughters/ Family (husband) (6)	Husbands (15)



Establish Scientific Validity of  
the Concept of:

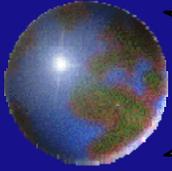
Culture as a Variable:

~~Dichotomous / Unidimensional~~

Continuous / Multidimensional

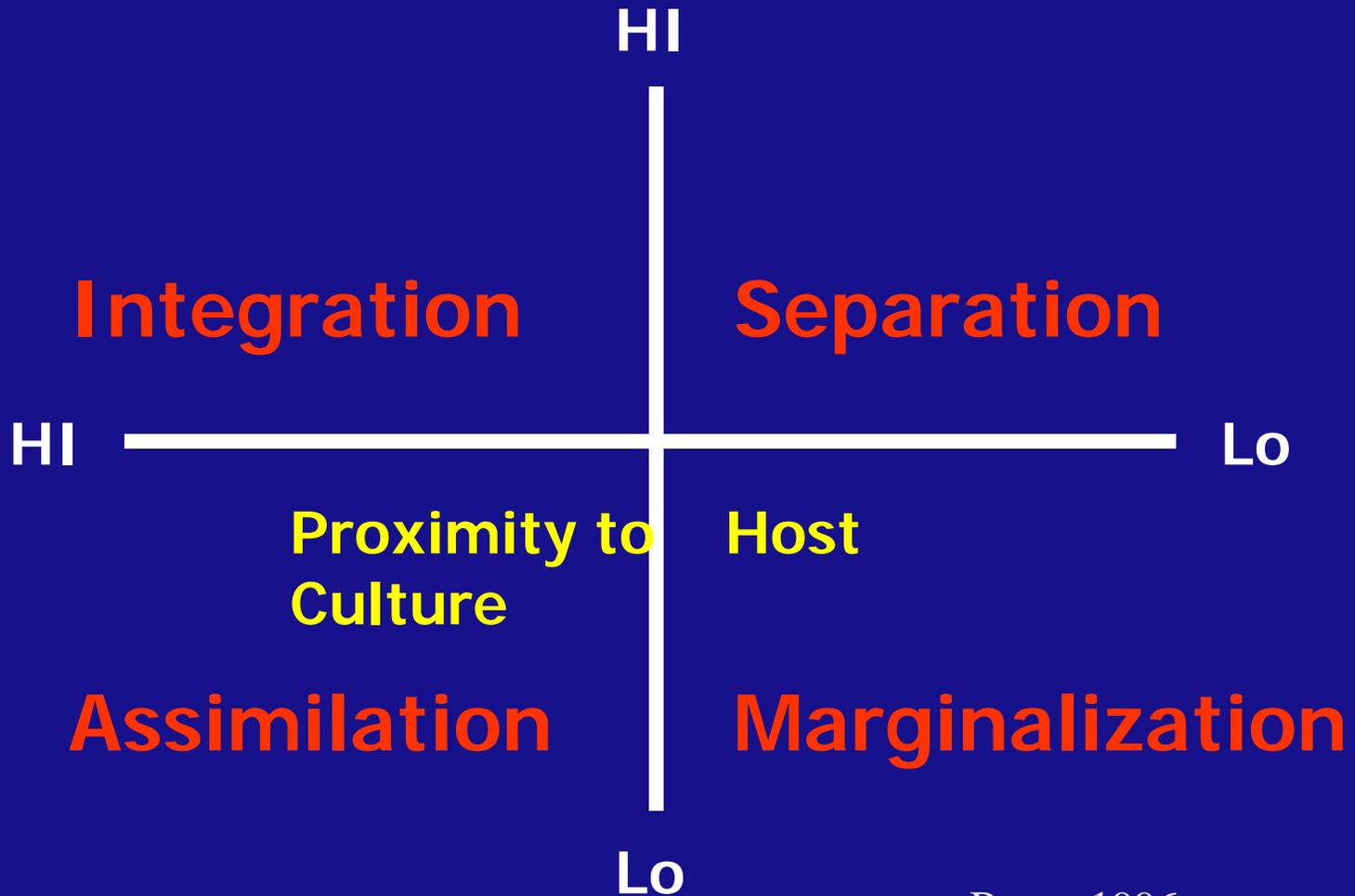
Dynamic and Situational



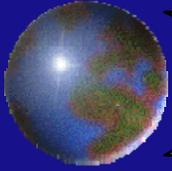


# Berry's Acculturation Model

**Co-National Identity**

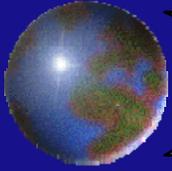


Berry, 1996



## *Future Directions:*

- ✓ Appreciate and understand cultural relativity and equal validity
  - ✓ Decision making styles regarding treatment
  - ✓ Clinician/patient/family relationships
  - ✓ Communication patterns with family and friends re: cancer experience
  - ✓ Coping styles and modes of seeking help
  - ✓ Social support - from whom, when and what form



## ***Implications for Practice and Research***

- ✓ Develop skills to formulate culturally relevant questions
- ✓ Learn cultural idioms for distress
- ✓ Frame forms of assistance and social support interventions in culturally congruent and acceptable manner
- ✓ Develop asset based v. deficit based interventions
- ✓ Have review group members skilled in inductive and qualitative research paradigms and cross-cultural methodologic issues



## Matsumotos from Maui, HI



**The Matsumoto family from Maui, HI., visiting the 442nd Memorial in Little Tokyo: Willard Matsumoto (background) was in Company "H". Matsumoto's wife, Jeanette, is supporting their grandson, Brandon, who is standing on his father, Erick Yamashige.**

Standing  
on the  
shoulders  
of our  
heritage  
through  
our families



**PATH  
For  
Women**



**Survivors**



**and**



**THRIVERS!!**

