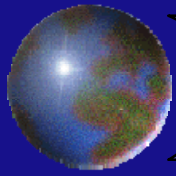


Culture and Survivorship

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

October 4-5, 2006

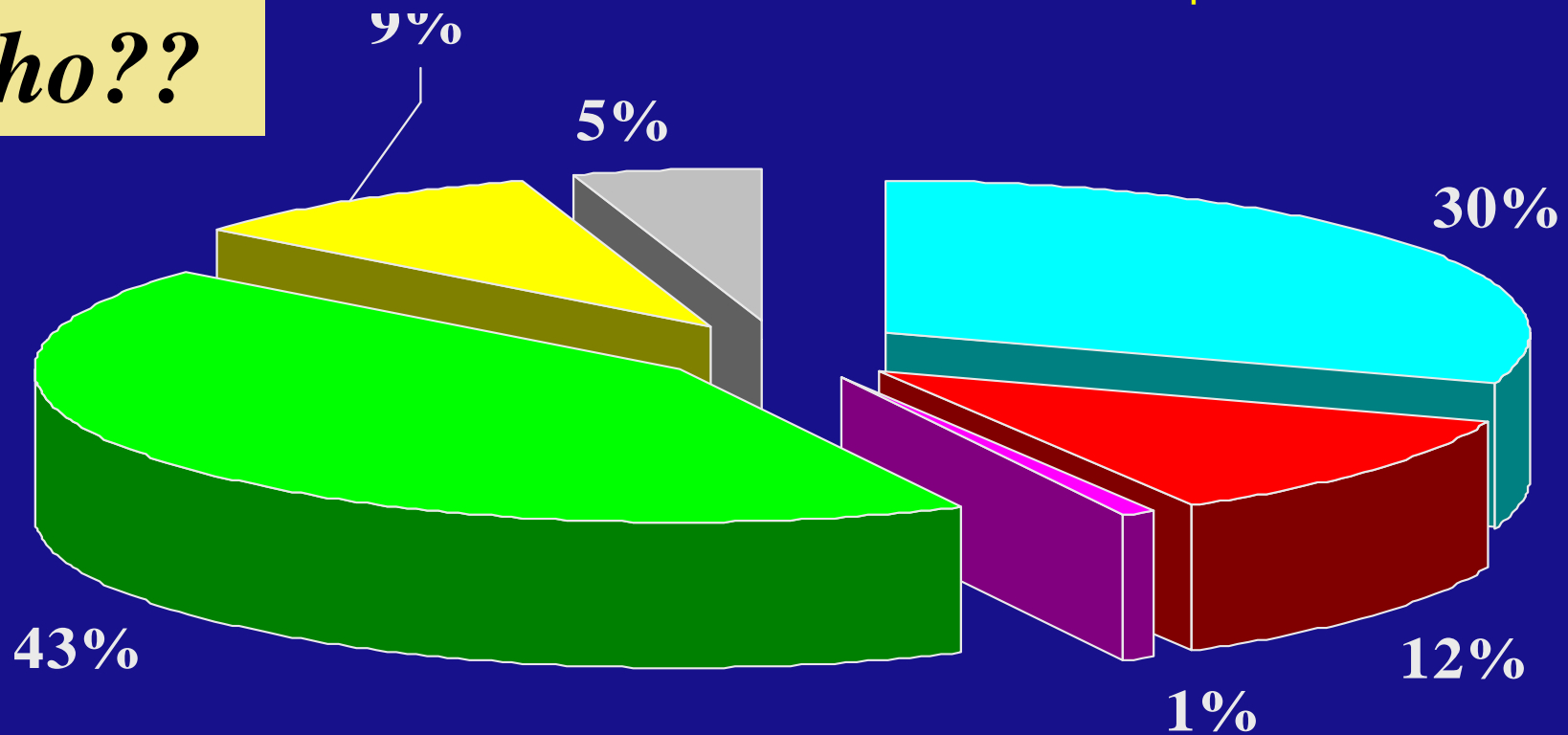
Marjorie Kagawa-Singer, Ph.D MN, RN
UCLA School of Public Health
and
Asian American Studies Department



Los Angeles Demographics 2000

Population = 9,519,338

Who??



Whites (Non-Hispanic)

Asian or Pacific Islander

American Indian & Alaska Native

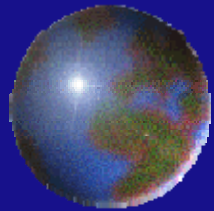
Hispanic

Black or African American

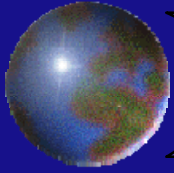
Two or More Races

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

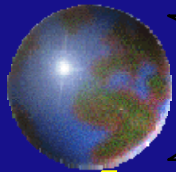
⚡ Health services

Survivorship, Support Groups, and Quality of Life Lit Search

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

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

Valdez, A., PubMed, search Oct, 2006



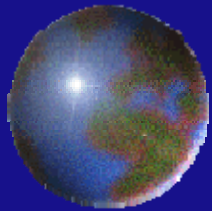
And what evidence do we have on the survivorship experience for underserved populations at Each Stage of the Cancer Care Continuum ?

Cultural

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

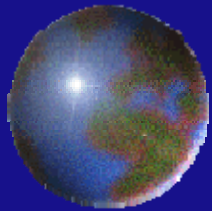
Context

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

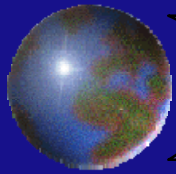


- **Samples:** primarily low income African American and Latinos
 - **Aggregation** of groups confound findings
 - **Age and gender** differences are significant and unstudied
 - Sources of **support** need to be differentiated from types of support
- (Bloom, 1995) (con't)

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

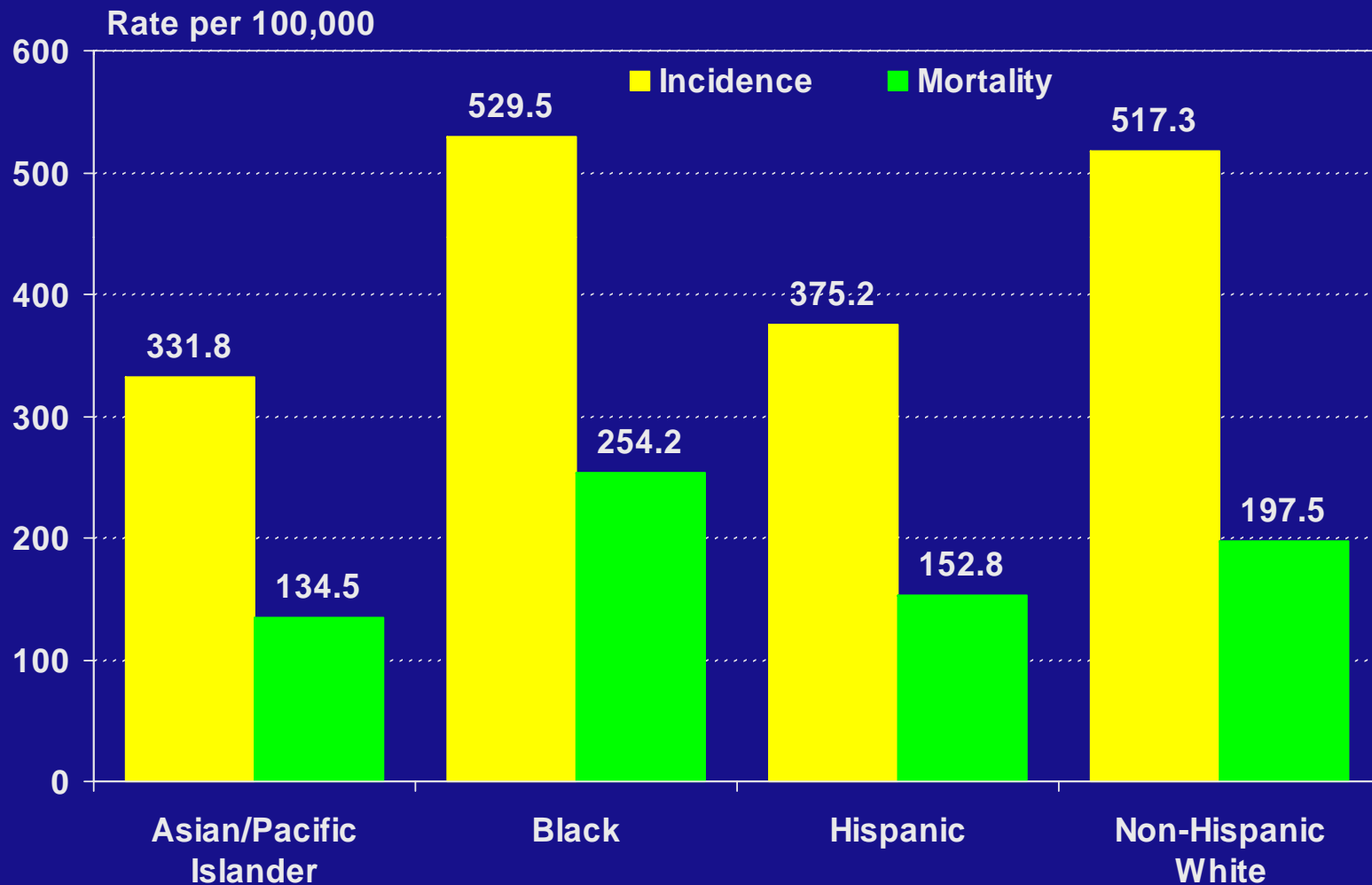


- Need for family focus and recognition
EVERYONE has a culture (Gotay, 2000)
- **Spirituality** is fundamental strength in Latino and African American cultures
- Establish **cultural equivalence** of concepts such as "QOL" and "survivorship" and of measures themselves (Padilla & Kagawa Singer, 2004)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

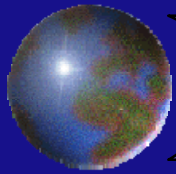


All Cancers

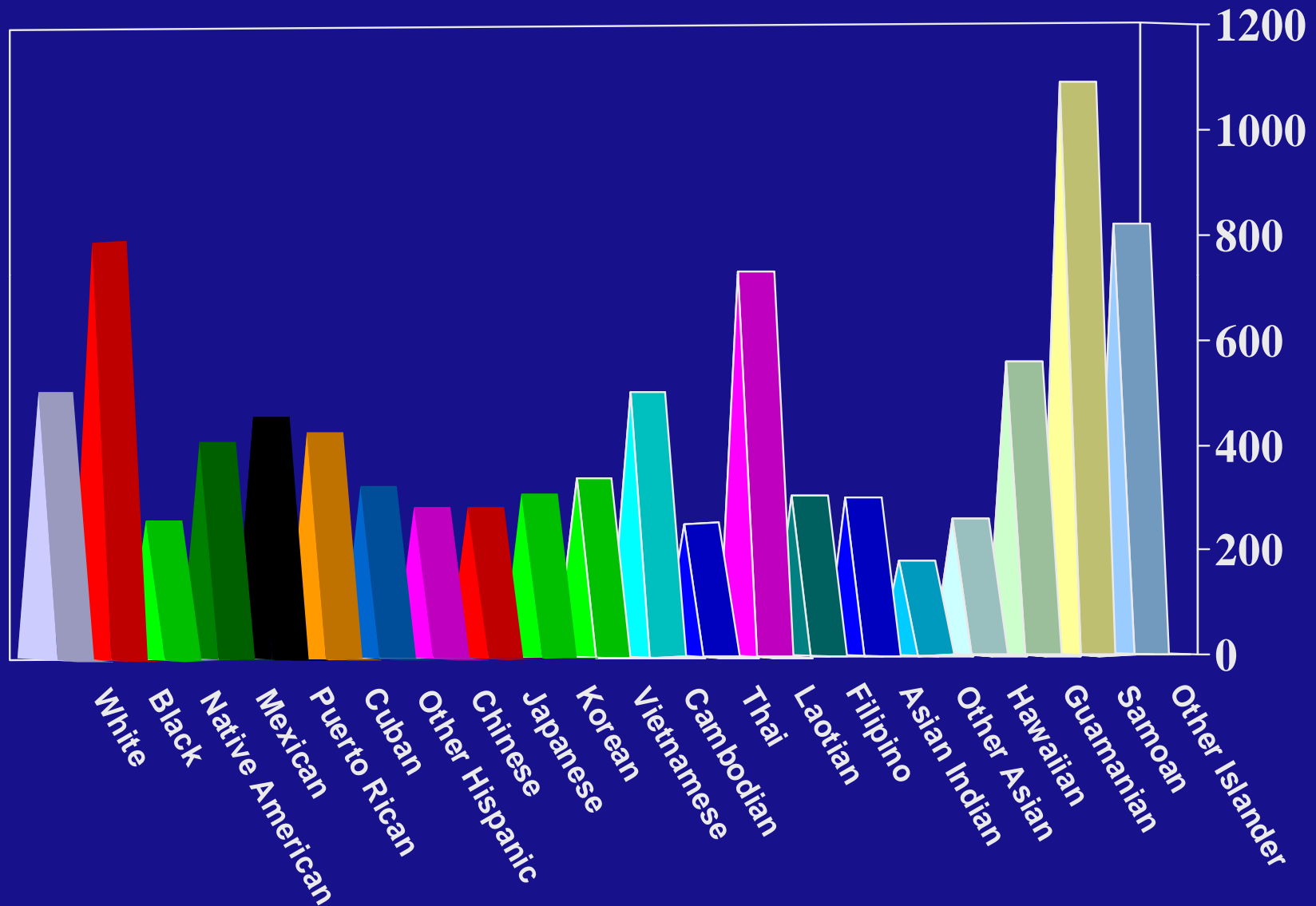
Five-Year Average Annual Age-Adjusted Incidence and Mortality Rates per 100,000, California, 1997-2001

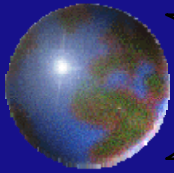


S. Kwong, 2004 – California
Tumor Registry



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



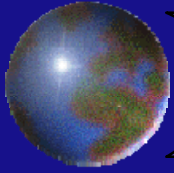


Equal Cancer Treatment = Equal Cancer Outcomes

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

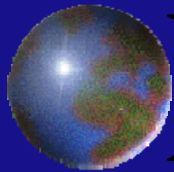


Brawley OW, Freeman HP. Race and outcomes: is this the end of the beginning for minority health research? *J Natl Cancer Inst* 91: 1908-9. 1999.



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



August Special!

Buy One, Get One Free!

Heart Scan + Lung Scan \$699
Second Heart Scan + Lung Scan Free!

Using advanced, multi-slice, multi-detector scanning equipment, CT Screening International (CTSi) provides detailed images that can help you prevent medical problems before they become critical. The Board Certified M.D. radiologists at CTSi are leaders in their field. ***The procedure is fast, non-invasive and affordable. It could save your life!*** Offer valid through August 31, 2002. Purchased and free scan must be redeemed on same visit. Single scan also available at special price.

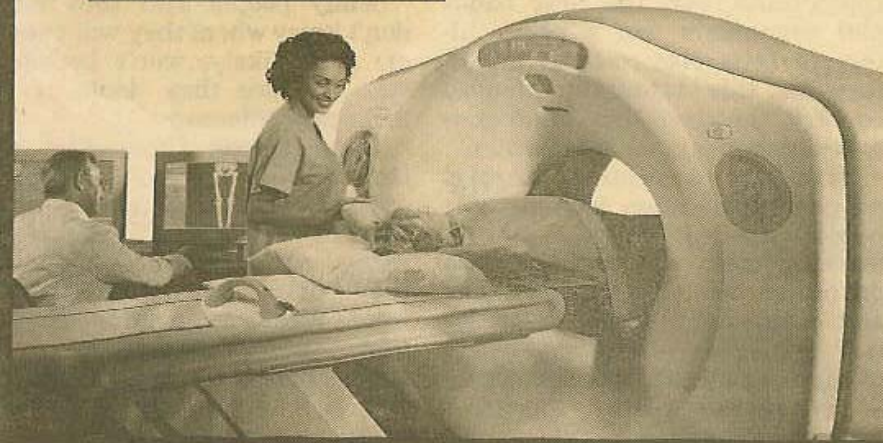
CTSi Centers Located In:
Beverly Hills, Encino, Newport Beach, Pasadena

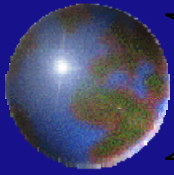
Call toll-free today!
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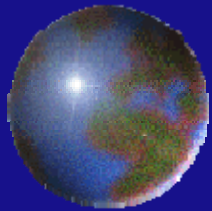







Clinical trials

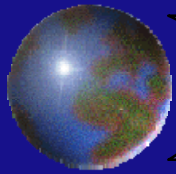
(McCaskill-Stevens, *J of Clin Onc*
2005;23:5247-5254)

- 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



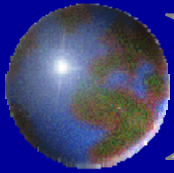
End of Life Care in Communities of Color

- ? 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



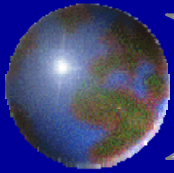
Key Definitions

- ★ **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



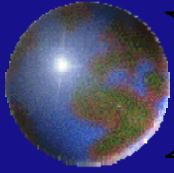
Culture affects:

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



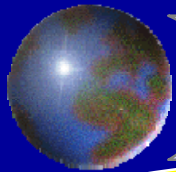
Culture affects:

- 🌐 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 =

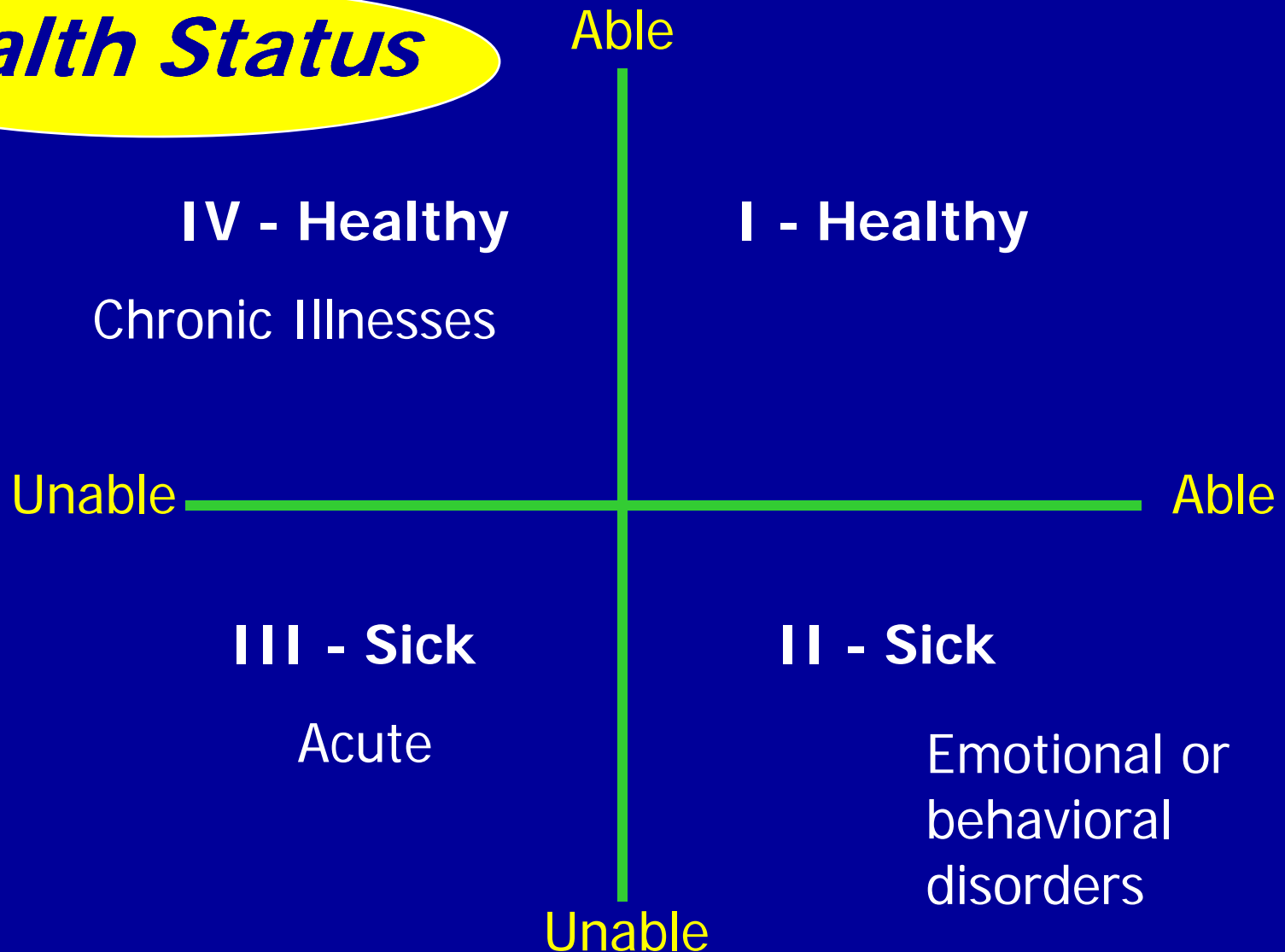
Ability to work towards life objectives and lead full and fulfilling lives as an essential part of one's social network

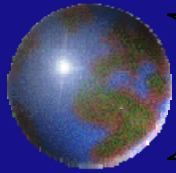


Social Function

Health Status

Physical Status



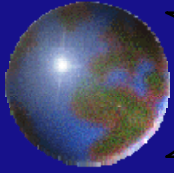


PAIN PERCEPTION

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

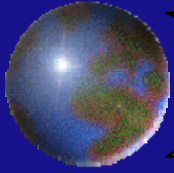
Davitz, et al, 1976 Scale 1-7 Vignettes





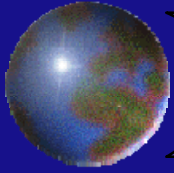
U.S.A. Values

- ☐ Independence
- ☐ Self-reliance
- ☐ Autonomy
- ☐ Happiness



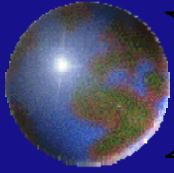
Values of Everyone Else

- ☐ Collectivism
- ☐ Interdependence
- ☐ Community



Values of Other Cultures Regarding Health

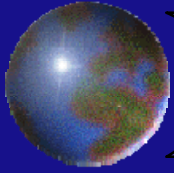
- ☐ Individual life is not sacred
 - group welfare is foremost
- ☐ Decisions are made by group-consensus
- ☐ All life is suffering



Culture

TOOL which its members use to assure their:

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

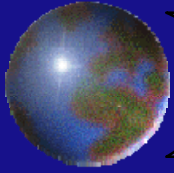


2 Dimensions of Culture:

- ❑ **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



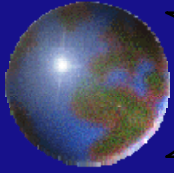




Culture is comprised of:

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

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



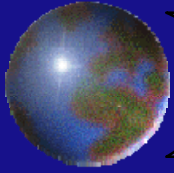
Ethnic groups of color in the U.S.

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



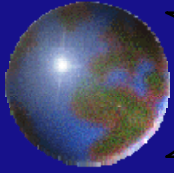
American Beats Kwan for the Gold!
1998 Olympics - US Women's Figure Skating





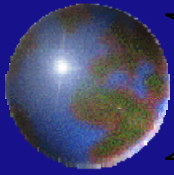
How does culture affect the science of survivorship studies?

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



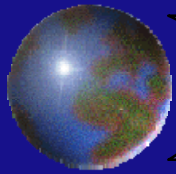
Study of Cultural Differences

- ☐ 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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needs of its customers –
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France
0800-574-121

Germany
0800-100-3366

All Other European Countries
0870-6060244

Japan
00531-63-6014

Hong Kong
800-908-211

Australia
1-800-122-465

Singapore
800-6363-029

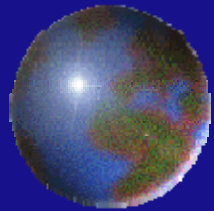
China
108006100238

All Other Pacific Rim Countries
632-636-9630

U.S. & Canada
1-800-409-3278

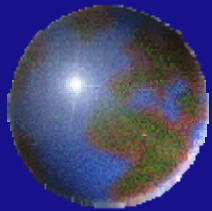
All Other Countries
1-602-528-3240





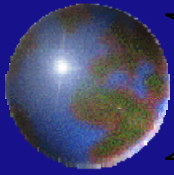
***What do we need to do
from this point forward
in addressing the needs
of the underserved?***

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



Research Designs

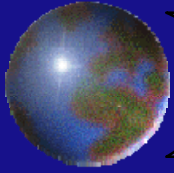
- Culturally valid theories and constructs
- Mixed methods using mixed paradigms ~
 - Deductive
 - Inductive



Metaphor of Cultural Responses

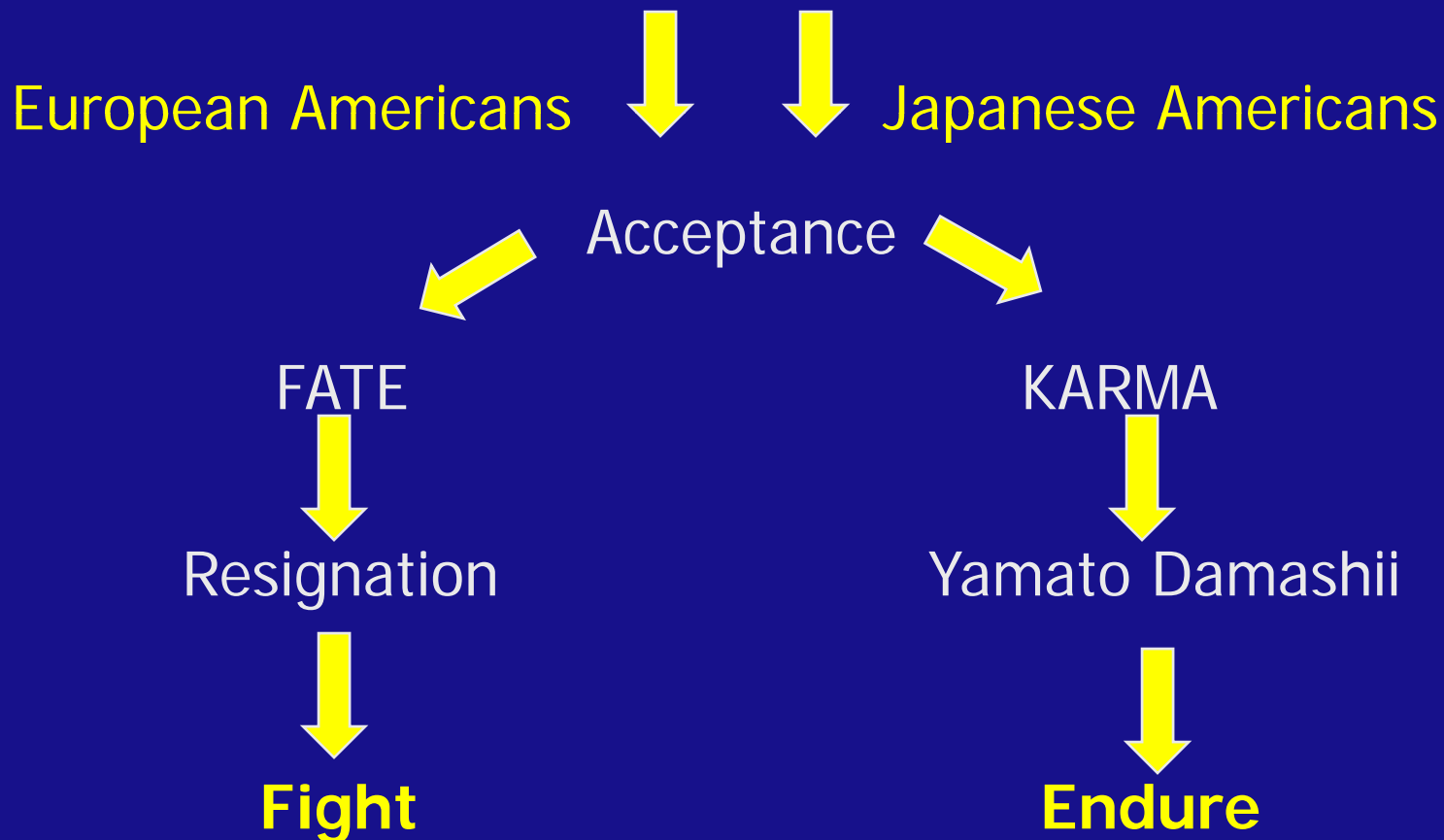
🌳 Oak and 🌳 Bamboo

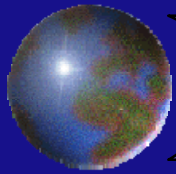




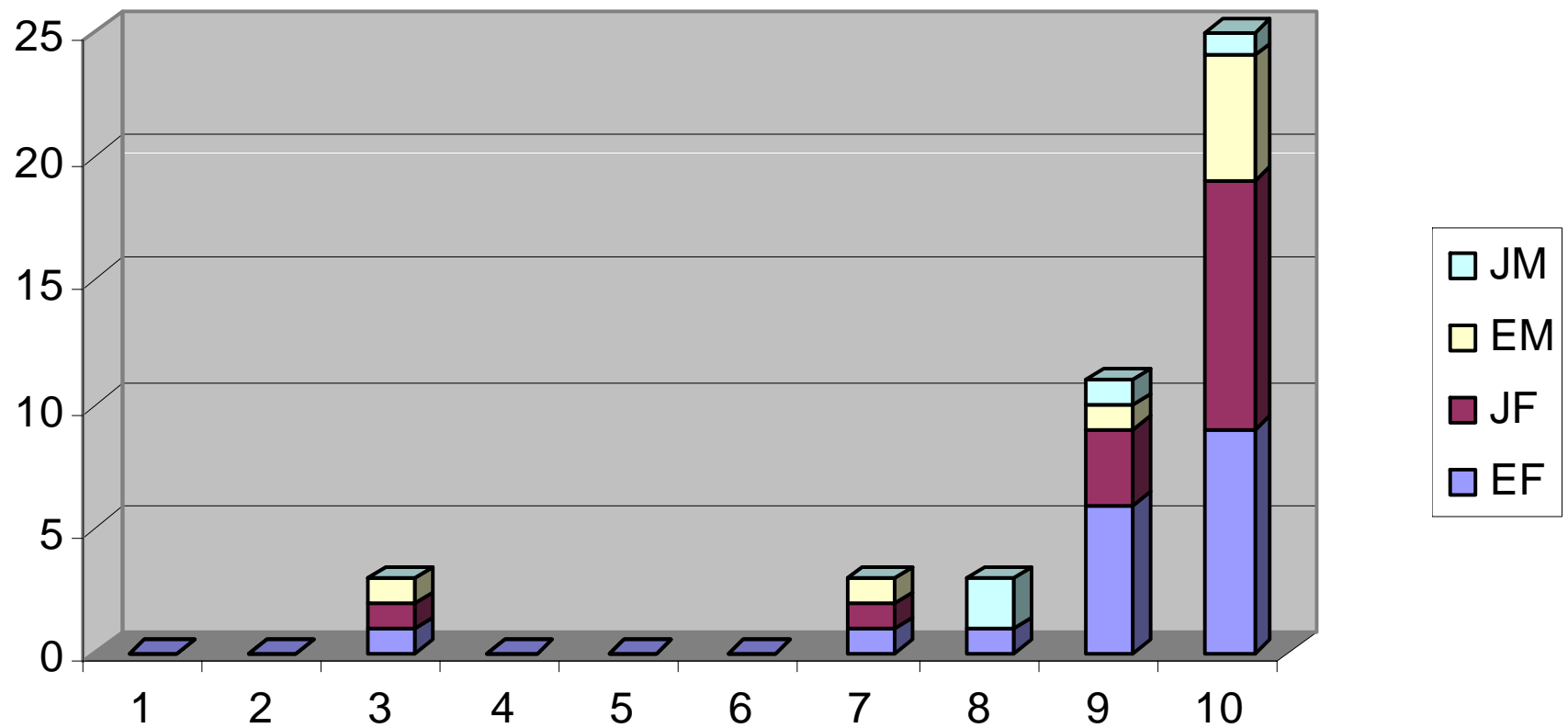
Summary of Cultural Responses

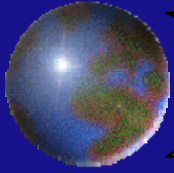
CANCER CRISIS





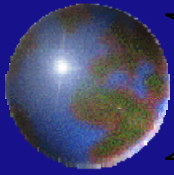
Self-Esteem - Rosenberg by



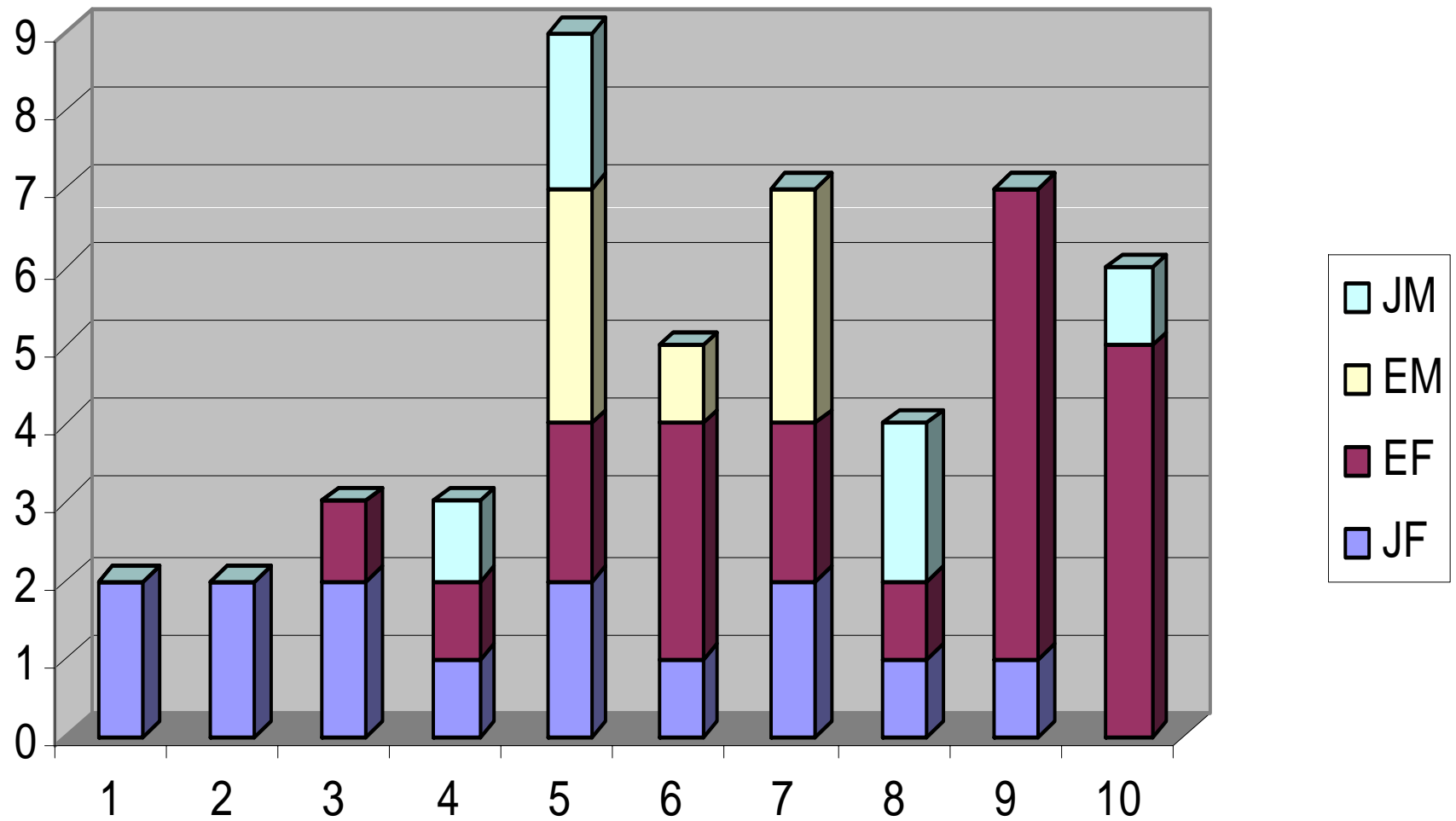


Ideal Qualities

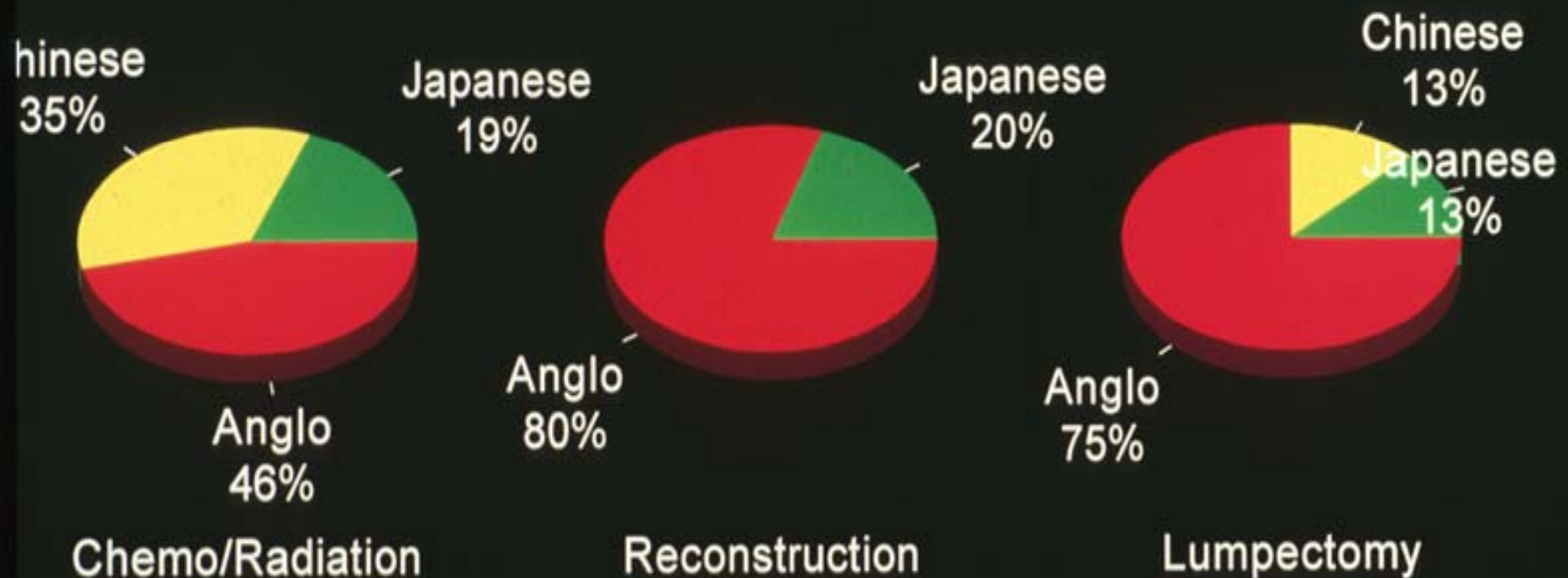
- Good self-esteem
 - Humble & No ego
- No complaining/
Patience
- Compassionate
- Personable
- Understanding
- Intelligent
- Intelligent
- Kind/ Responsible
- "Together"
- Happiness
- Independent/
Open-minded

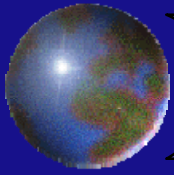


Distribution of Self-Evaluation Scores



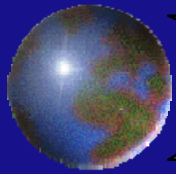
Treatment by Ethnicity





Differences that make a difference ~

FUNCTION (similar across sites)	FORM (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>

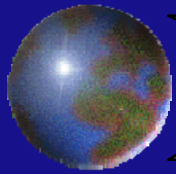


Relationship with Husbands of Chinese-, Japanese- & European-American Breast Cancer Survivors

Kagawa-Singer and Wellisch, 2002 Psycho-Oncology

Theme 1: Vulnerability – h & w emotional dependency

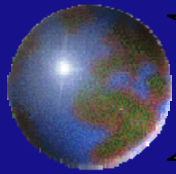
Domain	Japanese-	Chinese-	Euro-American
A. Emotional Dependency	Same for all three groups		
B. Cultural permission for dependency	No Self-sacrifice and nurturer		Yes
C. Husband's mode of help-seeking	Family of origin > wife	Silent	More expressive and > wife
D. What husbands provide	Same for all three: 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

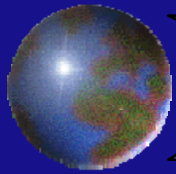
Domain	Japanese-	Chinese-	Euro-Americams
A. Mutual emotional give and take	Same for all three groups		
B. Harmony and Intimacy	Harmony rather than intimacy predominates		Intimacy predominates v. harmony
C. Communication	Non-Verbal – Inshin denshin in Japanese and Zhih Yi in Chinese		Direct and verbal 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
A. Empathy	Expectations of wives not met by husbands		
B. Recognition of individuality	Invalidation of individuality	"cut a little slack" but 'abandoned' to own resources	No time out from ongoing stress in relationship
C. Perceived types of support from H	Pragmatic problem-solving assistance and tangible aid – driving, housecleaning, also reassurance and calm		
D. Sources of support for W	Friends/co-workers (3)	Daughters/Family (husband) (6)	Husbands (15)



Establish Scientific Validity of
the Concept of:

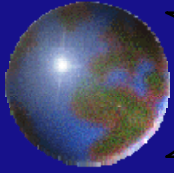
Culture as a Variable:

~~Dichotomous / Unidimensional~~

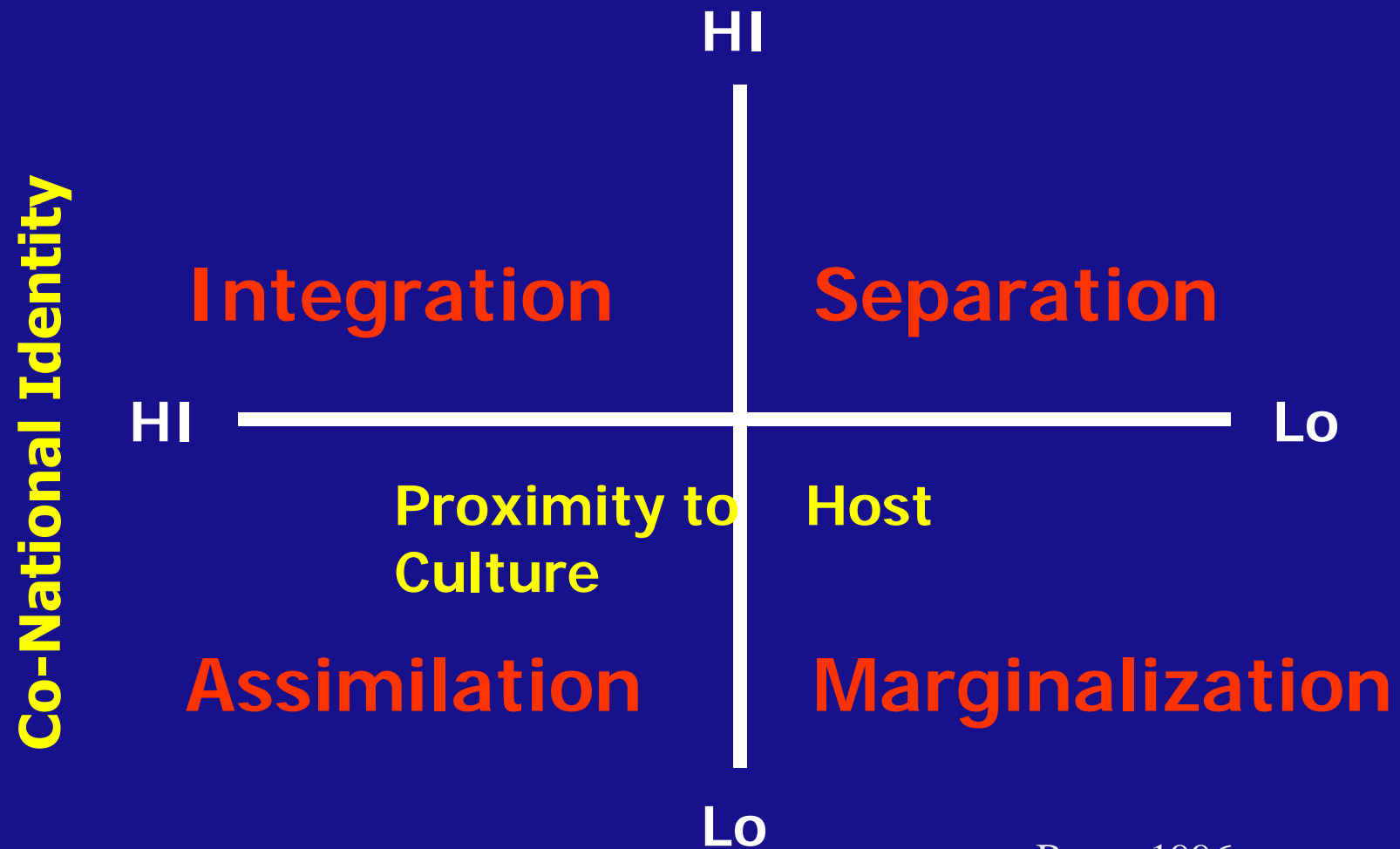
Continuous / Multidimensional

Dynamic and Situational

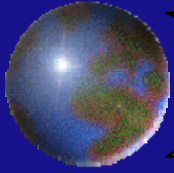




Berry's Acculturation Model

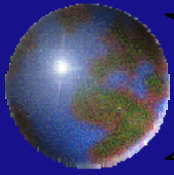


Berry, 1996



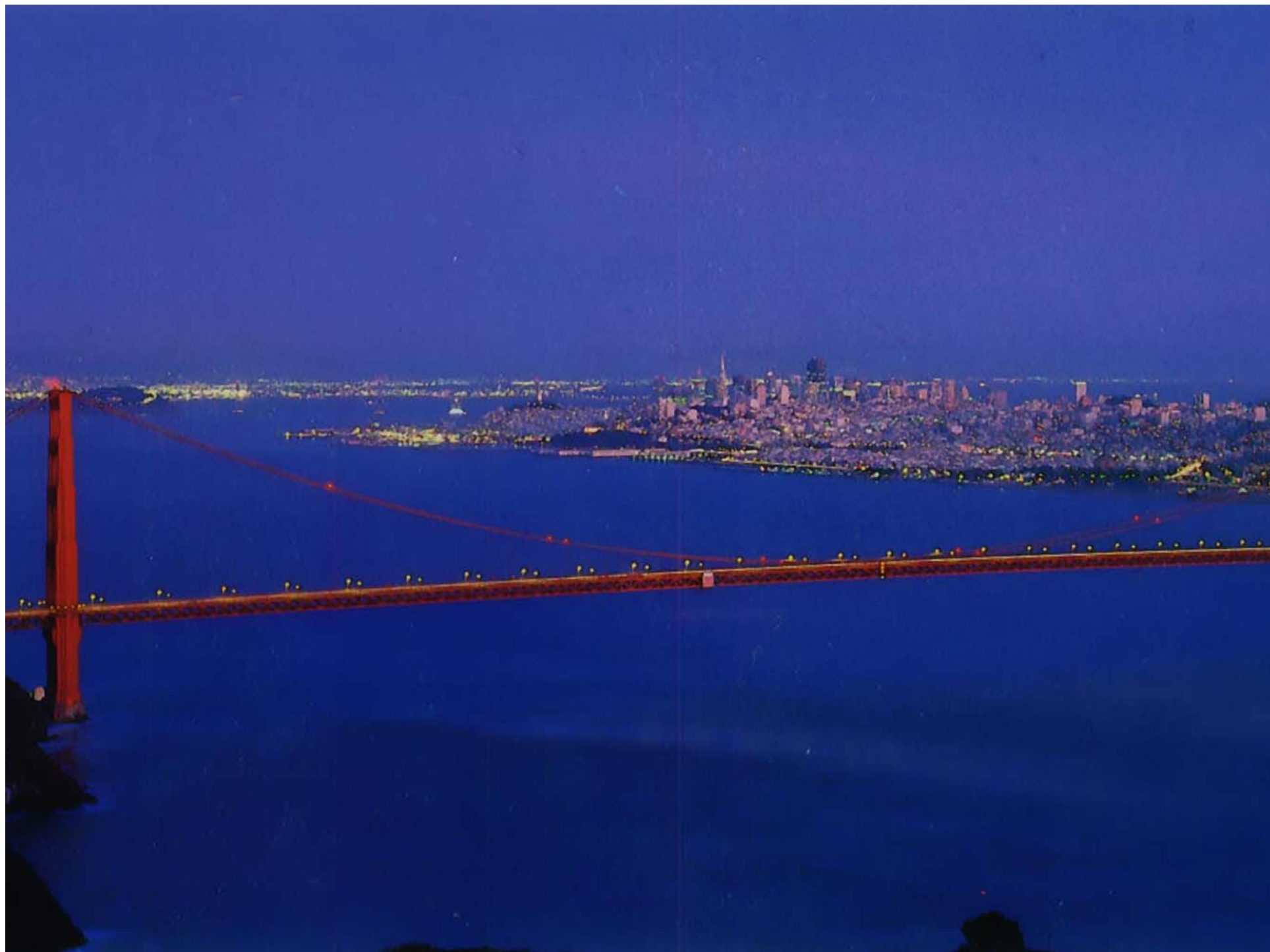
Future Directions:

- ✓ 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!!

