Culture and Survivorship

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

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and
Asian American Studies Department
Los Angeles Demographics 2000
Population = 9,519,338

Who??

- Whites (Non-Hispanic): 43%
- Asian or Pacific Islander: 30%
- American Indian & Alaska Native: 5%
- Hispanic: 9%
- Black or African American: 1%
- Two or More Races: 12%
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
- Psychosocial
- Health services
- Patterns of care
- Quality of care
Survivorship, Support Groups, and Quality of Life Lit Search

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

General Lit Search*

| Survivorship                  | 44,952         |
| Support Groups                | 2,828          |
| Quality of Life               | 2,398          |
| TOTAL                         | 50,178         |

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

1. Diagnosis
2. Treatment
3. Rehabilitation/ Support
4. Palliative Care
5. End of Life Care
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
- UUnequal treatment = UUnequal survival

**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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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
Health Status

Social Function

I - Healthy

IV - Healthy

Chronic Illnesses

Unable

Emotional or behavioral disorders

II - Sick

III - Sick

Acute

Unable

Able

Unable

Able

Kagawa-Singer, 1994
<table>
<thead>
<tr>
<th>Country</th>
<th>Phys.</th>
<th>Psych.</th>
<th>Interference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vietnam</td>
<td>3.81</td>
<td>4.84</td>
<td>Low</td>
</tr>
<tr>
<td>Japan</td>
<td>3.73</td>
<td>4.64</td>
<td>Low</td>
</tr>
<tr>
<td>Taiwan</td>
<td>3.54</td>
<td>4.06</td>
<td>Low</td>
</tr>
<tr>
<td>Thailand</td>
<td>3.20</td>
<td>4.40</td>
<td>Low</td>
</tr>
<tr>
<td>Puerto Rico</td>
<td>3.06</td>
<td>4.80</td>
<td>Hi</td>
</tr>
<tr>
<td>USA</td>
<td>3.00</td>
<td>4.43</td>
<td>Hi</td>
</tr>
</tbody>
</table>

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 unpredictable and inevitable predictable and controllable.
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
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

European Americans  ↓  Japanese Americans

Acceptance

FATE → Resignation

KARMA → Yamato Damashii

Fight → Endure
Self-Esteem - Rosenberg by Sex and Ethnicity
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

- Chinese: 35%
  - Chemo/Radiation: 46%

- Japanese: 19%
  - Reconstruction: 80%

- Anglo: 80%
  - Lumpectomy: 75%

- Chinese: 13%
  - Lumpectomy: 13%
## Differences that make a difference~

<table>
<thead>
<tr>
<th><strong>FUNCTION</strong></th>
<th><strong>FORM</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>(similar across sites)</td>
<td>(tailored to community)</td>
</tr>
<tr>
<td>Provide Optimal Treatment</td>
<td>Delivery</td>
</tr>
<tr>
<td></td>
<td>Information/messenger</td>
</tr>
<tr>
<td>Provide effective support</td>
<td>Who, what, when, and to whom</td>
</tr>
<tr>
<td>Promote QOL</td>
<td>Domains and relative salience</td>
</tr>
<tr>
<td>Minimize discomfort of side effects</td>
<td>Meaning of suffering Communication styles</td>
</tr>
</tbody>
</table>
## Theme 1: Vulnerability - h & w emotional dependency

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

<table>
<thead>
<tr>
<th>Domain</th>
<th>Japanese-</th>
<th>Chinese-</th>
<th>Euro-Americans</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Mutual emotional give and take</td>
<td>Same for all three groups</td>
<td></td>
<td></td>
</tr>
<tr>
<td>B. Harmony and Intimacy</td>
<td>Harmony rather than intimacy predominates</td>
<td>Intimacy predominates vs. harmony</td>
<td></td>
</tr>
<tr>
<td>C. Communication</td>
<td>Non-Verbal – Inshin denshin in Japanese and Zhih Yi in Chinese</td>
<td>Direct and verbal communication is valued</td>
<td></td>
</tr>
<tr>
<td>D. Role expectations</td>
<td>Wife’s role clearly differentiated as emotional nurturer and husband as source of security</td>
<td>Ability to be dependent on husband</td>
<td></td>
</tr>
</tbody>
</table>
# Relationship with Husbands of Chinese-, Japanese- & European-American Breast Cancer Survivors

## Theme 3: Sources of dissonance: Meeting needs

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

Kagawa-Singer and Wellisch, 2002 Psycho-Oncology
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

Integration | Separation

Proximity to Host Culture

Assimilation | Marginalization

HI

Lo

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
Standing on the shoulders of our heritage through our families.
PATH
For Survivors
Women
and
THRIVERS!!