Health Literacy and Cross-Cultural (Mis)Communications

Why Do you Want to Know and What are you talking about?

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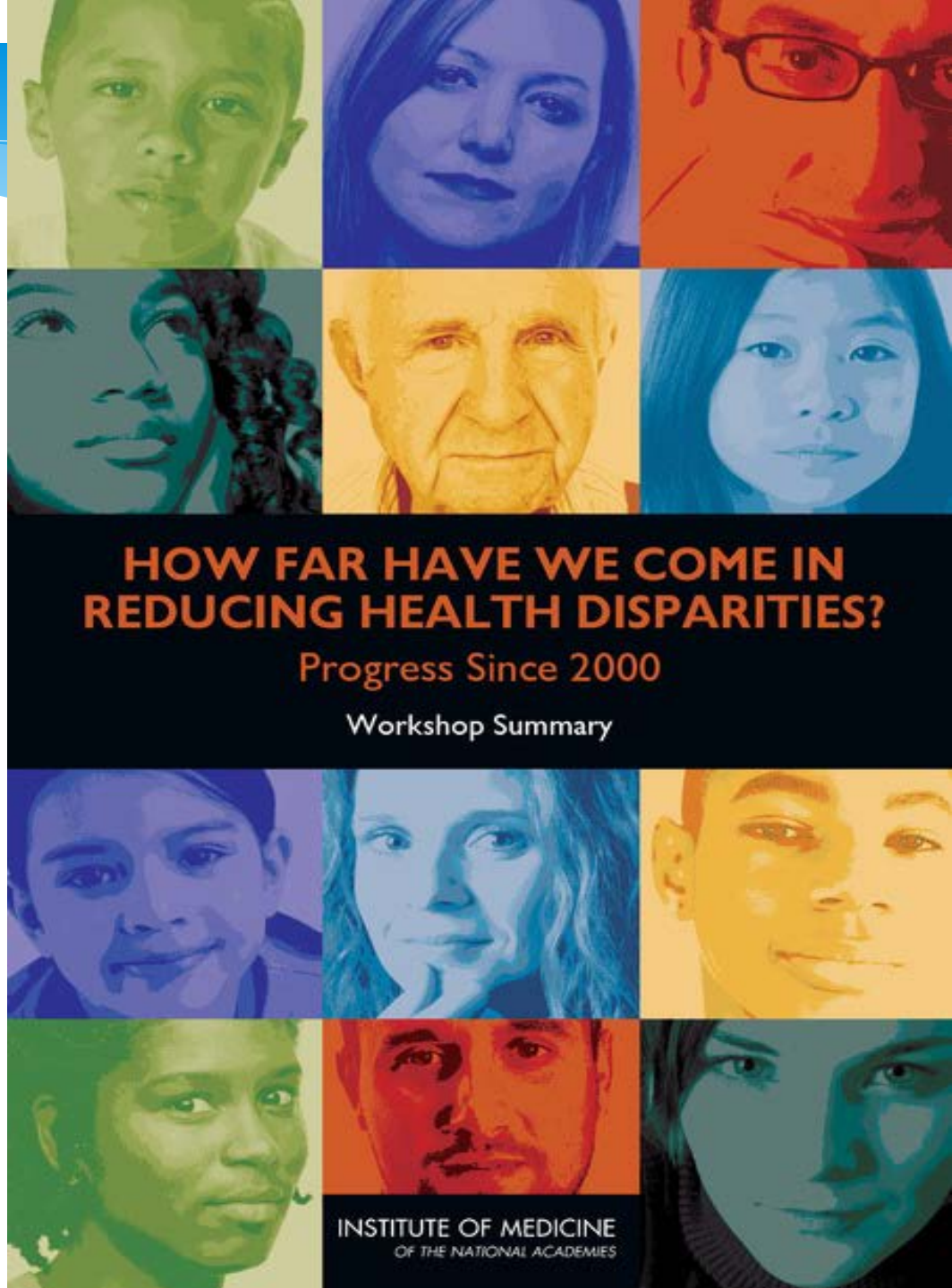
In 40 years of research to eliminate health disparities, we have made no progress.

Leonard Syme, 2008

IOM Workshop Summary, 2012



Definition of "Health Literacy"

https://health.gov/communication/literacy/quickguide/factsbasic.htm

* **Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.**[1]
  * Dependent on individual and systemic factors:
    * Communication skills of lay persons and professionals
    * Lay and professional knowledge of health topics
    * ***Culture***
  * Demands of the healthcare and public health systems
  * Demands of the situation/context

Centrality of Health Literacy to Cancer Care Navigation

- **Health literacy affects people's ability to:**
  - **Navigate the healthcare system,**
    - including filling out complex forms and locating providers and services
  - Share personal information, such as health history, with providers
  - Engage in self-care and chronic-disease management
  - Understand probability and risk
- **Health literacy includes numeracy skills**. calculating cholesterol and blood sugar levels, measuring medications, and understanding nutrition labels.
  - Choosing between health plans or
  - Comparing prescription drug coverage
  - Knowledge to calculate premiums, copays, and deductibles.

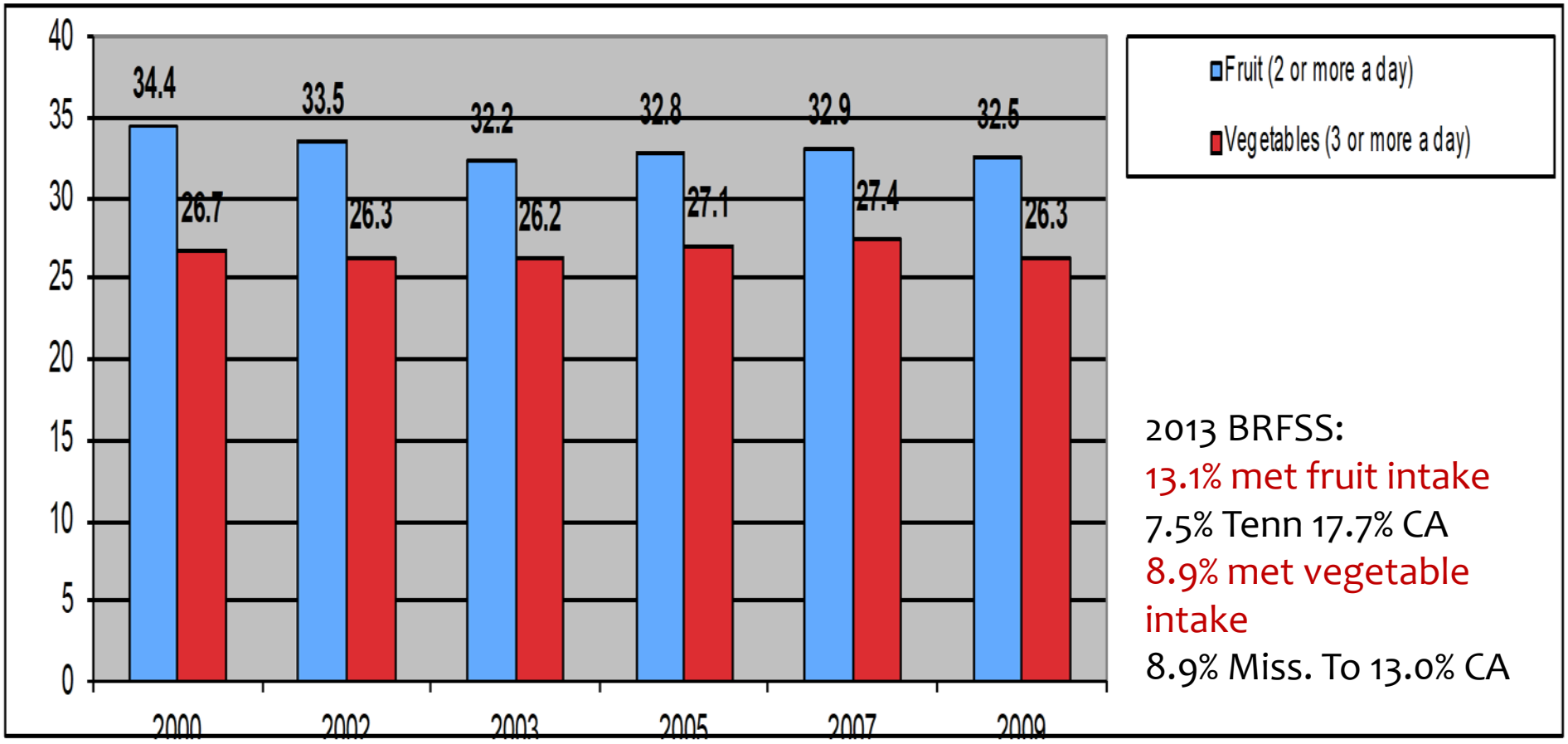
- https://health.gov/communication/literacy/quickguide/factsbasic.htm

Scope of the Problem

* Only 12 percent of adults have Proficient health literacy.
  * Nearly 9/10 adults may lack the skills needed to manage their health and prevent disease.
  * 14% of adults (30 million people) have Below Basic Health Literacy.

National Assessment of Adult Literacy, Kirsch et al 1993

Trends in Consumption of Five or More Recommended Vegetable and Fruit Servings for Cancer Prevention, Adults 18 and Older, US, 2000-2009 – *We've gotten worse*



2013 BRFSS:
13.1% met fruit intake
7.5% Tenn 17.7% CA
8.9% met vegetable intake
8.9% Miss. To 13.0% CA

Source: Centers for Disease Control and Prevention (2010), State-Specific *Trends in Fruit and Vegetable Consumption Among Adults* —. United States, 2000–2009

So: *WHO sets the Standards and style of presentation*?

- WEIRD people do most of the research
  - **"WHITE – EDUCATED – INDUSTRIALIZED – RICH – DEMOCRATIC"**
- 96% of the researchers in health psychology and 98% of the subjects tested in theory development are from WEIRD countries, and
- Represent only 12% of the world's population

Ethan Watters, http://www.psmag.com/magazines/pacific- standard- cover- story/joe- henrich- weird- ultimatum- game- shaking- up- psychologyeconomics- 53135

Henrich, Heine and Norenzayan, We Aren't all WEIRD, Nature 2010

Relationship between Health Literacy and Culture

1. We are a **multicultural** society. The **monocultural** approach denies culture and the context and complex determinants of health disparities
2. Need to view cultural differences as **assets** - sources of strength for patients and their families and
3. Employ techniques that would more productively be applied when transmitting information in cross-cultural encounters.

Goals for Health Literacy

To promote a patient's capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions for our *diverse* populations ~

1. Recognize **fundamentally different** cultural constructs

2. Listen **first** to create **authentic** dialogue

Constructs of patient/family – practitioner Interactions based on a covenant rather than a contract –

Richard Payne, MD

Basic Cultural Values

* U.S.A.
  * Independence
  * Individualism
  * Autonomy
  * Happiness

Basic Cultural Values

* **Everyone else**
  * Interdependence
  * Community – group welfare
  * Group consensus
  * All life is suffering

Results of Pasick's 2009 Study

* **Statistically on the deductive quantitative analyses, no significant difference between groups,**

* **On the qualitative analyses, none of these constructs held significance/relevance for the Filipinas or Latinas.**

Culture is Fundamental to Human Existence

“

There is no such thing as human nature independent from culture”

Three Universals for Well-Being

Social resources and structures that provide every individual:

1. Survival and security
2. Integrity and Meaning
3. Belonging as an integral part of a social network

Trustworthiness as Clinician and/or Researcher Requires

* Demonstration of:

1. Your ability to respect their individuality and truly "go where he lives"[1]
2. Learn WHAT and HOW they want the information they seek
3. Develop a covenant ~ not a contract[2] (SIGN a POLST)

1. Kagawa Singer and Blackhall, 2010
2. R. Payne, Personal communication, 2010

Cross Cultural Equivalence of Concepts in Health Behavior Theories

Pasick et al (2009) used a mixed method study to test the cross cultural equivalence of the 5 most common concepts in behavioral theories for mammography for Filipinas and Latinas

- Perceived benefit
- Perceived susceptibility
- Self-efficacy
- Intention
- Subjective norms

WHY are we missing culture in health research?

We lack:

- A scientifically grounded **concept of culture**
- **Integration of communities of interest** in true partnership to identify differences that make a difference
- **Measures** that accurately operationalize the aspects of culture that most affect the health issue of focus
- Studies that **test the hypothesis of cultural (individual, social, structural and ecologic) impacts** on health literacy and health outcomes

Culture is the "way of life and thought that we construct, negotiate ***institutionalize***, and finally end up calling '***reality***' " (Bruner, 1996:87)

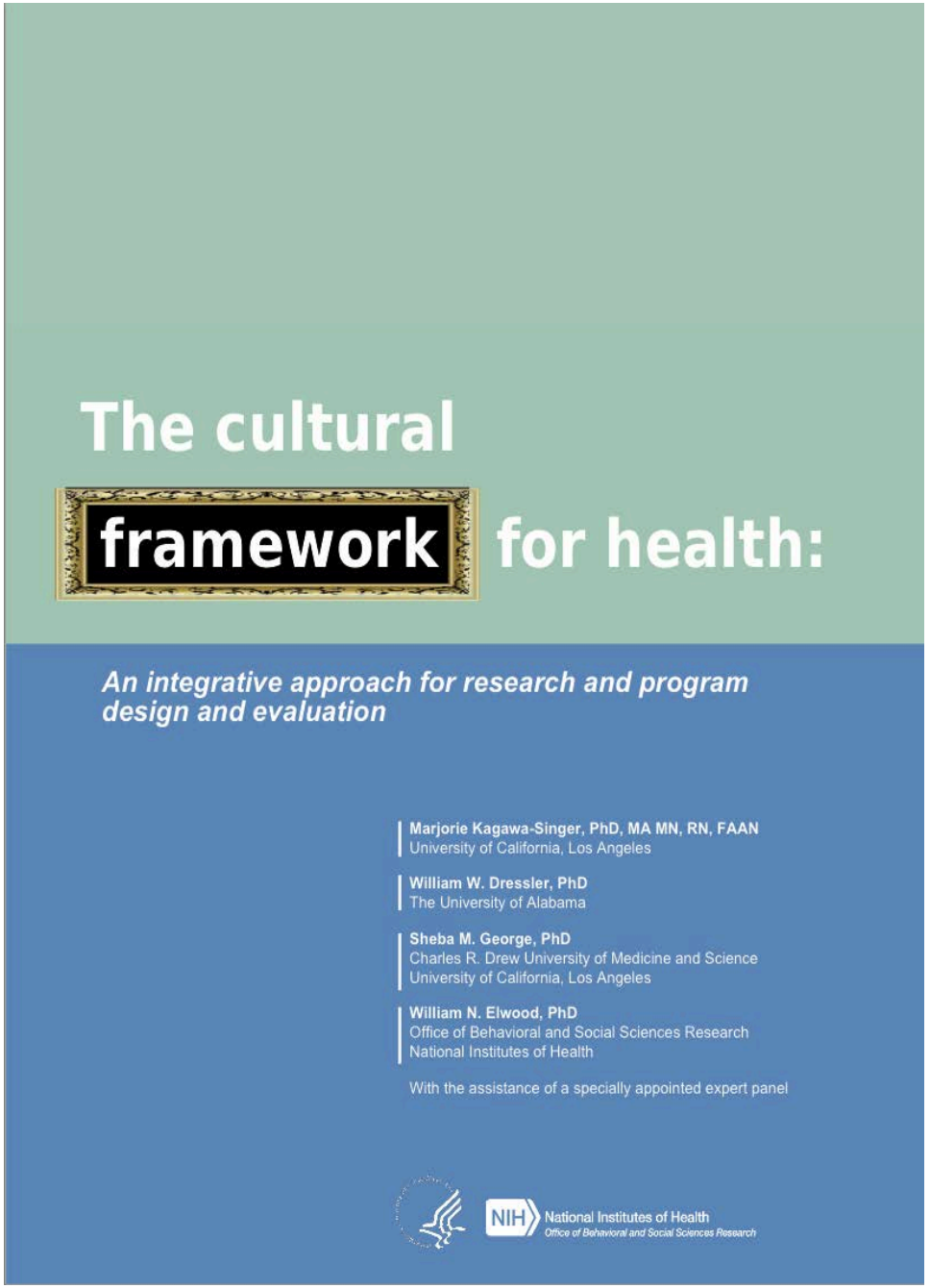
- **Despite its central role in explaining behavior:**

"No other variable used in health research is so poorly defined and untested as "culture".

- **Dressler, Gravlee, Ots , 2005, Hruska 2009**

In Health Research we do not have a clear application of culture because we do not have a clear definition of culture nor appreciation of its complexity

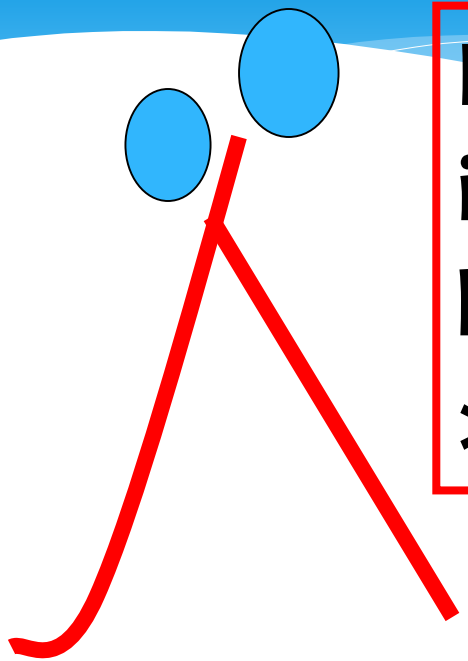
https://www.researchgate.net/publication/273970021_The_cultural_framework_for_health_An_integrative_approach_for_research_and_program_design_and_evaluation



6 Recommended Cultural Framework for Health Checklist for Research and Practice

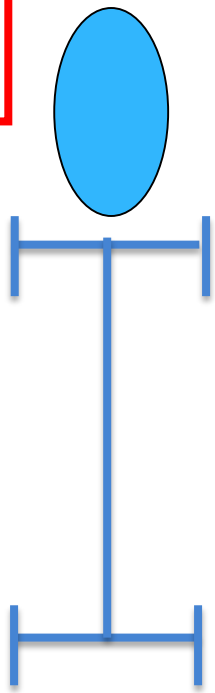
Before you embark on designing an intervention with a population different than the dominant white culture, answer the following 6 questions:

1. **Is the RATIONALE for the inclusion of culture clearly articulated in the problem statement?**
2. **Has a a definition of culture for the clinical or research objective(s) been articulated?**
3. **Are select theoretical and cultural constructs known?**
4. **Is there correspondence between salient theoretical and cultural constructs?**
5. **Is there a conceptual framework that specifies how salient constructs affect the health issue of focus? (e.g. Have independent variables, moderating and mediating effects been identified?**
6. **Are there cross culturally equivalent existing measures?**



Highly individualistic ~ but value >Interdependence

>Individualism



PERSONHOOD/Autonomy/Patient

Oak and Bamboo: Metaphors of Cultural Responses

Cancer Crisis

Western European American	Japanese American
Fate – cause is outside	Karma – cause is self-act
Resignation	"Yamato Damashii"
Fight	Endure

Kagawa Singer in Huff, Robert M., Michael V. Kline, and Darleen V. Peterson, eds. Health promotion in multicultural populations: A handbook for practitioners and students. SAGE publications, 2014.

Culture Matters - ”White Americans”

Scotland	Italy	Finland
Ireland	Greece	Spain
Iraq	Egypt	"Yugoslavia"
Israel	Iran	Afghanistan

Definitions of Race, Ethnicity, and Culture in Health

- **Culture** - DYNAMIC, multilayered and multidimensional **system** of beliefs, values, lifestyles, ecologic and technical resources and constraints that dynamically changes and adapts to circumstances and its members use to provide safety, security, and meaning FOR and OF life.
  - Environment, economy, technology, religion, language, etc.

- **Ethnicity** one's sense of identity as a member of a cultural group in a multicultural society

- **Race** - myth that scientifically assumes phenotype predicts genotype. This fact was debunked in the early 1940's. Biologically, **population groups, or clines** would be a more accurate term for geographically designated groups, such as populations which have similar adaptive physiologic responses and cultural practices due to ecologic niche conditions with advantage for genetic polymorphisms: G6-PD,thalassimias and orther findings in **precision medicine**.

- **Racism -** is a consequence of racial categorization, asserting power, ego fulfillment and status at the expense of others based upon skin color and phenotypic characteristics.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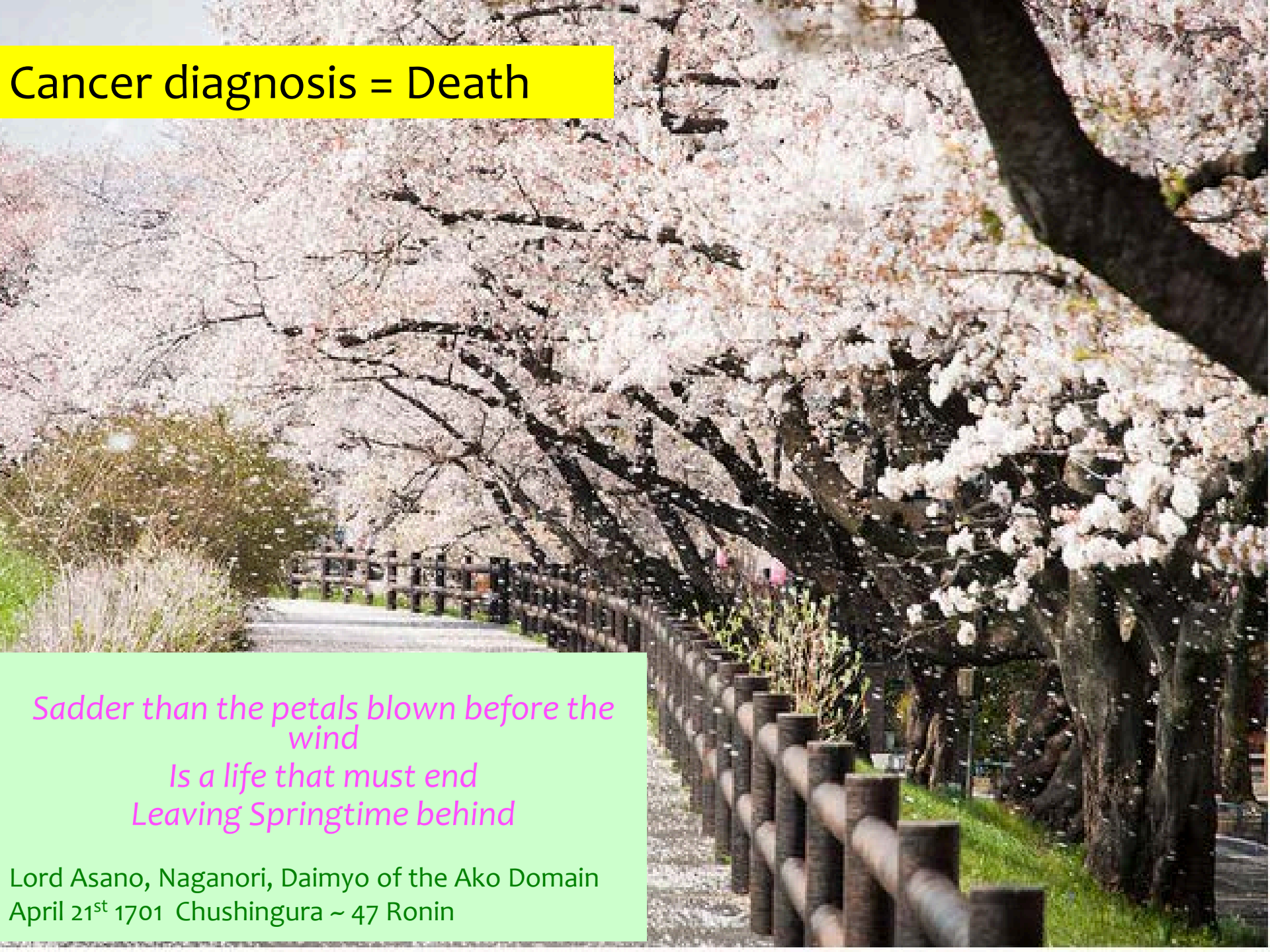
Cancer diagnosis = Death



Sadder than the petals blown before the wind
Is a life that must end
Leaving Springtime behind

Lord Asano, Naganori, Daimyo of the Ako Domain
April 21st 1701 Chushingura ~ 47 Ronin

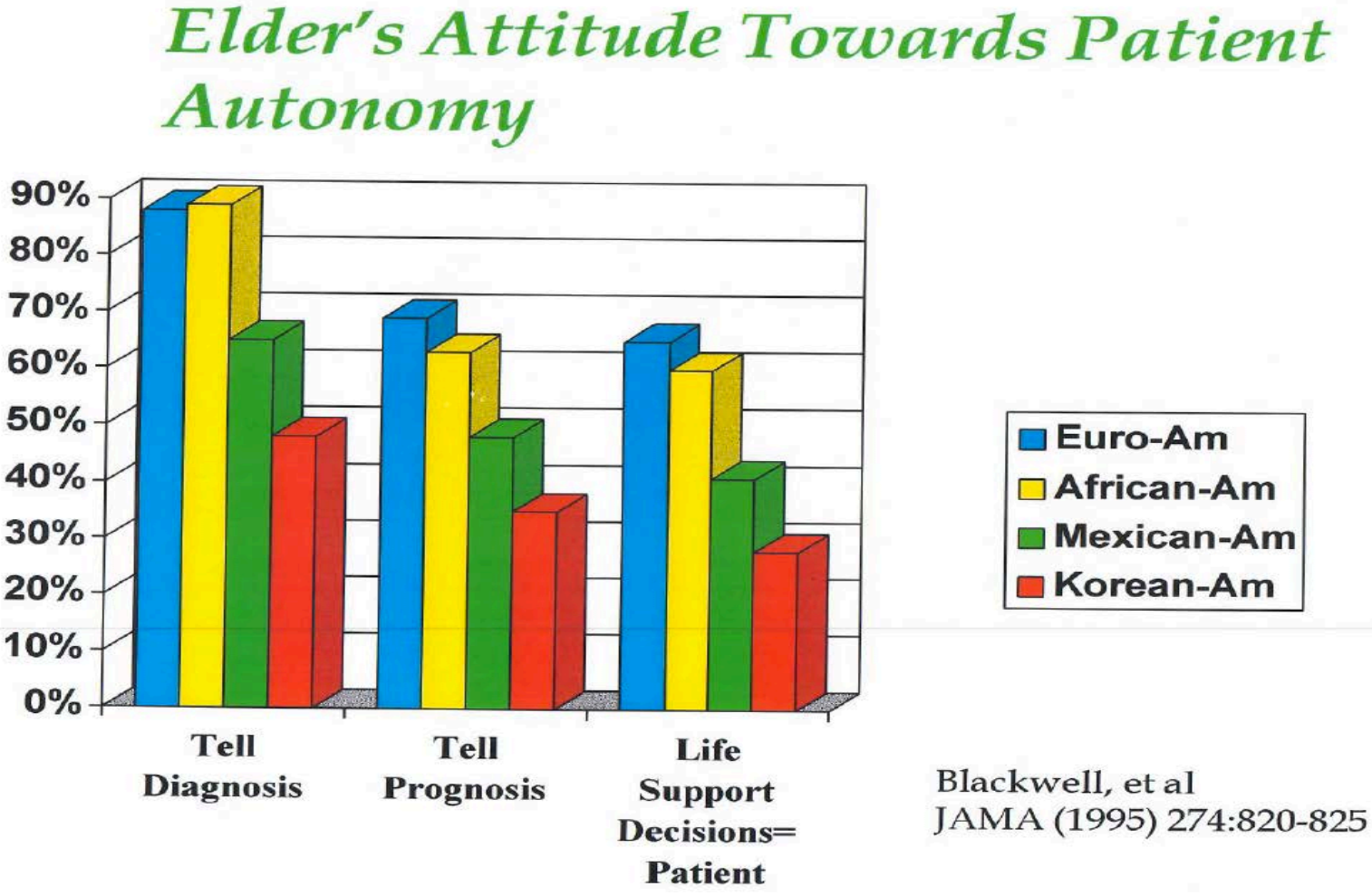
2 Functions of Culture: to provide its members meaning Of and For LIFE

- **Integrative** – those beliefs, behaviors and attitudes that one learns that provide a sense of integrity, belonging, and

- **Functional** – prescriptions of behavior that define a good person in that world view.

Kagawa Singer in Huff, Robert M., Michael V. Kline, and Darleen V. Peterson, eds. Health promotion in multicultural populations: A handbook for practitioners and students. SAGE publications, 2014.

Classic Blackhall Study on Truth Telling



Blackwell, et al
JAMA (1995) 274:820-825

Culture *IS*:

TOOL which its members use to :

1 – Assure their SURVIVAL & well-being

2 – Provide the MEANING *of* and *for* life

3 - A ***shared framework or lens*** that its members learn to use "see" the world and which informs, consciously and unconsciously, how to live life, why they live life, and how to resolve problems in doing so.

4 - Is ***socially, morally, and legally integrated*** into the structure of a society's institutions.

What Culture DOES:

- Provides the *social structure* that defines and coordinates the numerous *roles* of each of its members in relation to the group, *rules of social interaction* and *distribution of power*

- Expresses and provides meaning for the reality of its members through the *built environment including our institutions (schools and health care system)*

What Do Patients Want?

1. Not to be abandoned
2. Respected as an individual
3. Understood and cared for
4. Demonstrated trustworthiness

Disease Specific Concerns

1. Prognosis
2. How will this affect my life?
3. How will this affect my family's life?

What is FAMILY?

Transcendental Meditation Family

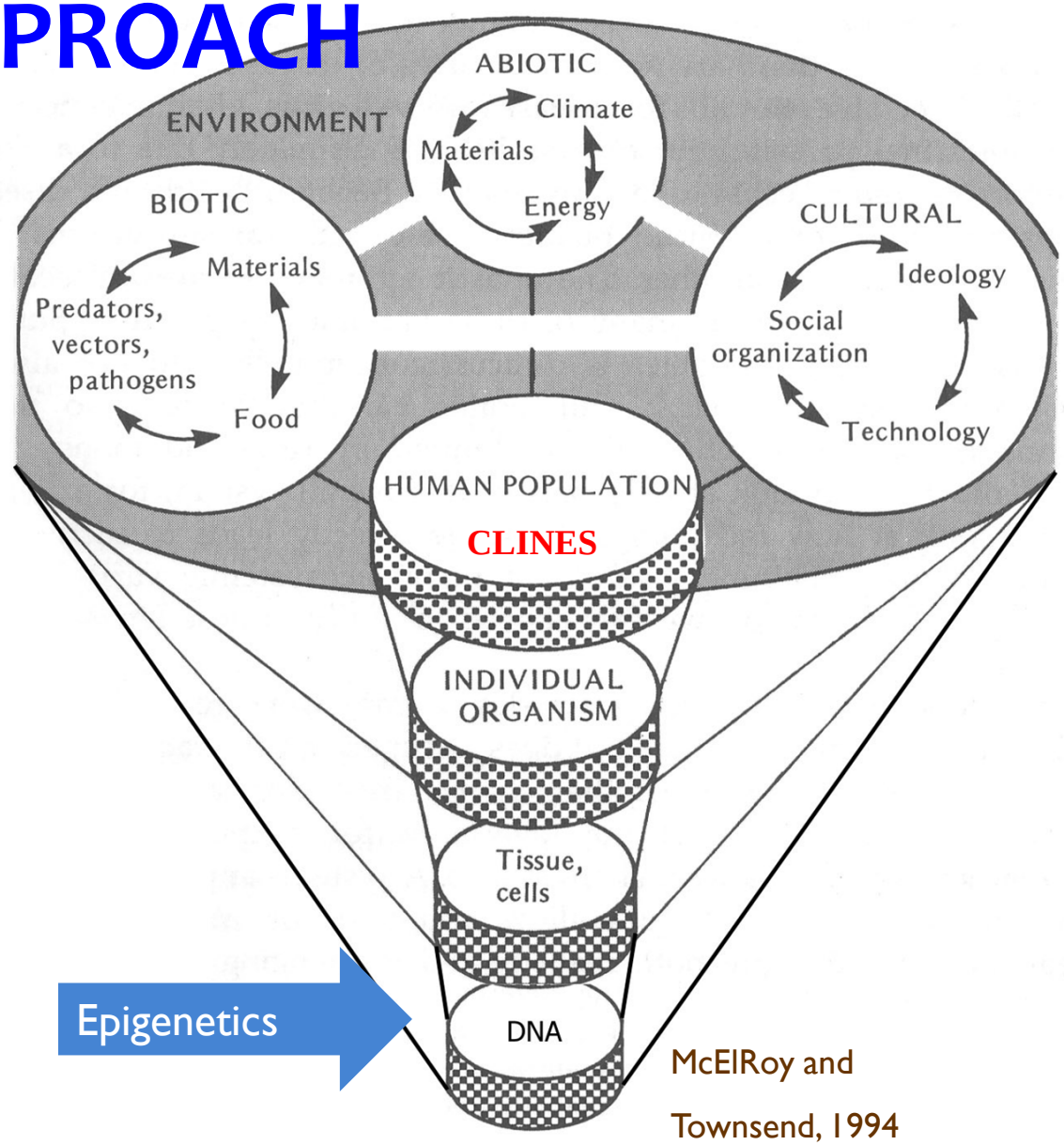
- BIOLOGIC
- RITUAL
- FICTIVE
- SELF-CREATED

SYSTEMS APPROACH

Culture =

adaptive system within a social, biological, and political environment that is multi-layered, multi-dimensional. and dynamic.

Culture MUST be understood within its *STRUCTURED* historical, social and political context.



McElRoy and Townsend, 1994 rev. K-S 2000


Cherubs, Chattel, Changelings
Hmong children in Sapa, Vietnam

“what do you wanta’ be if you grow up?”

“What do you wanta’ be if you grow up?”

Los Angeles Times

SOCIAL COMMENTARY: This Conrad cartoon depicts two children, victims of poverty and violence, contemplating their futures against long odds.

Comparison of Physician Discussion-making and Disclosure at End of Life after adjustment *

Odds Ratio (95% Confidence interval)	**English-speaking Japanese Americans**	**Japanese-speaking Japanese Americans**	**Japanese living in Japan**
Discuss end-of-life with a physician	0.73 (0.41, 1.31)	1.10 (0.62, 1.94)	1.0
Group decision-making model	1.11 (0.70, 1.74)	**0.63 (0.41, 0.97)**	1.0
Terminal prognosis disclosure to the patient **using words**	**8.79 (5.42, 14.3)**	**2.80 (1.79, 4.37)**	1.0
Terminal prognosis disclosure to the family **using words**	**2.01 (1.05, 3.88)**	1.03 (0.58, 1.83)	1.0

Matsumura, et al. 2000

To treat everyone equally, you must treat everyone uniquely

Communication of Emotionally Laden Information is:

7% Verbal

How many of you speak another language fluently?

38% Tone

65% Non-verbal

* **Body language differs with each!**

And culturally based ~ Whorf Sapir Hypothesis

Integrating Culture in *Practice* and Research~

EFFECTIVELY enables the patient and family to understand their **situation** and their **tasks** to mutually craft **alternatives and/or goals and next steps**

OUR TASK:

Relevant

Respectful and

Culturally responsive to the individual and their loved ones