

The Wisdom of *El Buen Morir*

***Intercultural Dignity* in End of Life Care**

*7th Annual Advances in
Palliative Care Conference*

Silvia Austerlic

***Senti-Pensante* Connections**

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Objectives

- Reflect about the role of culture and cultural differences in EOL Care.
- Introduce the *Model of Cultural Wholeness* to deepen understanding of cultural dimensions at play when providing direct services.
- Present professional skills & discuss cultural implications for a more effective practice.

Content

- I. Culture and Cultural Differences
- II. Model of *Cultural Wholeness*
- III. Skills for Becoming a
Culturally Empathic Bridge
- IV. Experiential Activity
- V. Recommendations

The Wisdom of *El Buen Morir*

“This visit affirmed to me that hospice philosophy and care is not a modern ‘created need,’ but is rooted in indigenous traditions and a deep spirituality, expression of an innate wisdom that knows how to be there for others at a time when human touch and compassionate presence make a world of difference, and is valuable in all times and cultures.”

Silvia Austerlic
Stories from the Field
HSCC Heart of the Matter
October 2011

What is Culture?

The Iceberg Concept of Culture

Like an iceberg,
nine-tenths of culture is below the surface.

Surface Culture
Most easily seen
Emotional level - low

Food, dress,
music, visual arts,
drama, crafts,
dance, literature,
languages, celebrations, games



Shallow Culture
Unspoken Rules
Emotional level - high

courtesy, contextual conversational patterns, concept of time, personal space, rules of conduct, facial expressions, nonverbal communication, body language, touching, eye contact, patterns of handling emotions, notions of modesty, concept of beauty, courtship practices, relationships to animals, notions of leadership, tempo of work, concepts of food, ideals of child rearing, theory of disease, social interaction rate, nature of friendships, tone of voice, attitudes toward elders, concept of cleanliness, notions of adolescence, patterns of group decision-making, definition of insanity, preferences for competition or cooperation, tolerance of physical pain, concept of "self", concept of past and future, definition of obscenity, attitudes toward dependents, problem solving roles in relation to age, sex, class, occupation, kinship, and ...

Deep Culture
Unconscious Rules
Emotional level - intense

Cultural Diversity

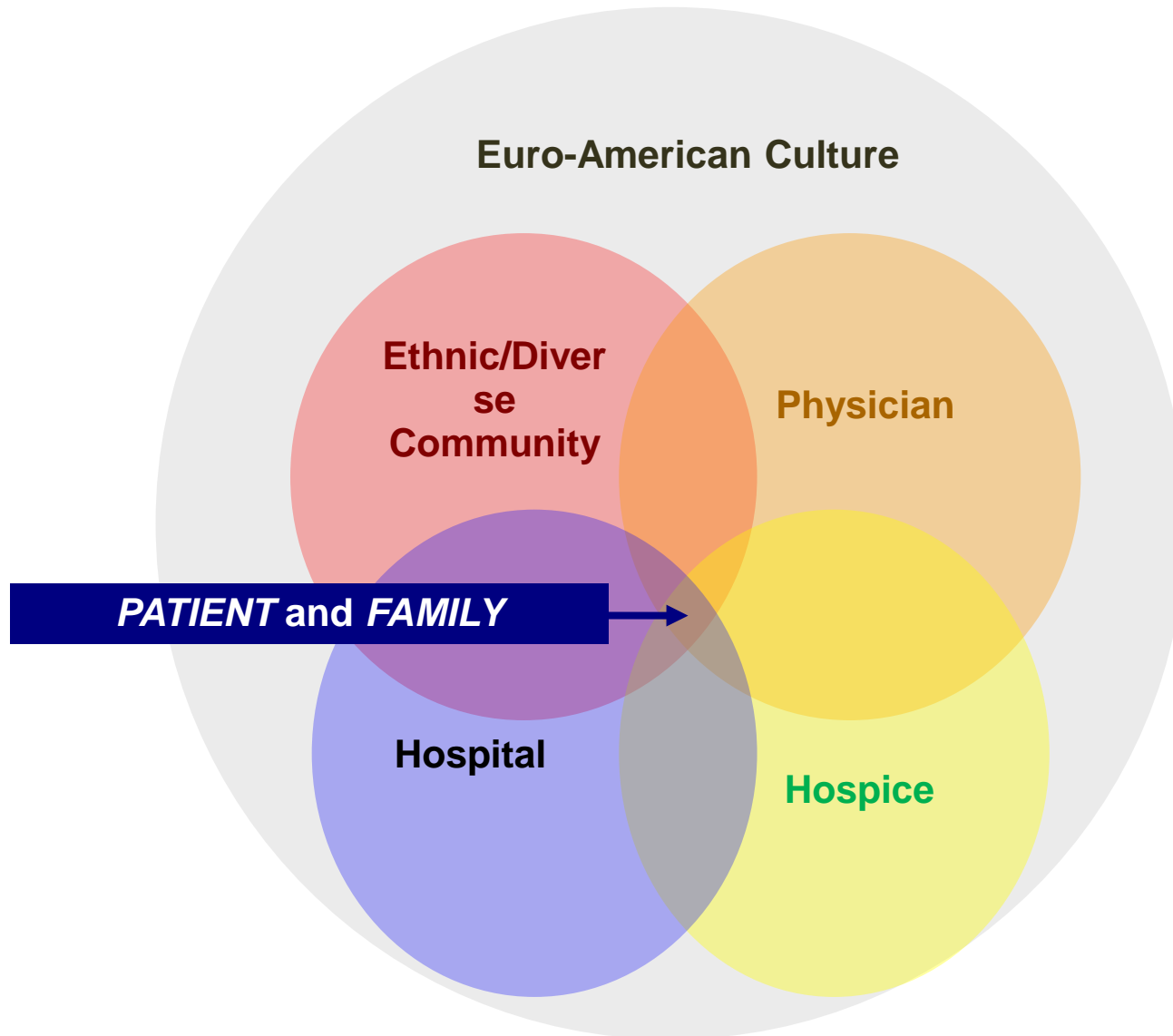
“In the United States of America, multiple cultures coexist, overlap, and sometimes contradict each other. Yet, just as the fish does not know it exists in water until it is pulled out, people are often unaware of the culture in which they live until they experience **cultural differences.**”

Integrating Spirituality into Multiculturalism
Fukuyama & Sevig (1999)

Developmental Model of Intercultural Sensitivity (M. Bennett)

Ethnocentric			Ethnorelative		
Denial	Defense	Minimization	Acceptance	Adaptation	Integration
My cultural experience is the only one that is real and valid. There is little to no thought of “other.”	“We” are superior and “they” are inferior. One feels threatened and is highly critical. What is strange may be labeled as stupid.	Other cultures are trivialized or romanticized. One tends to deny differences (e.g., “color blind”) and only seek similarities.	I accept but may not agree with other cultures. Generally, I am curious and respectful.	I “see” the world through different eyes and make intentional changes in my own behavior and values.	I easily move in and out of different cultural worldviews.

Cultural Diversity in End of Life Care



Cultural Differences in Models of Health Care

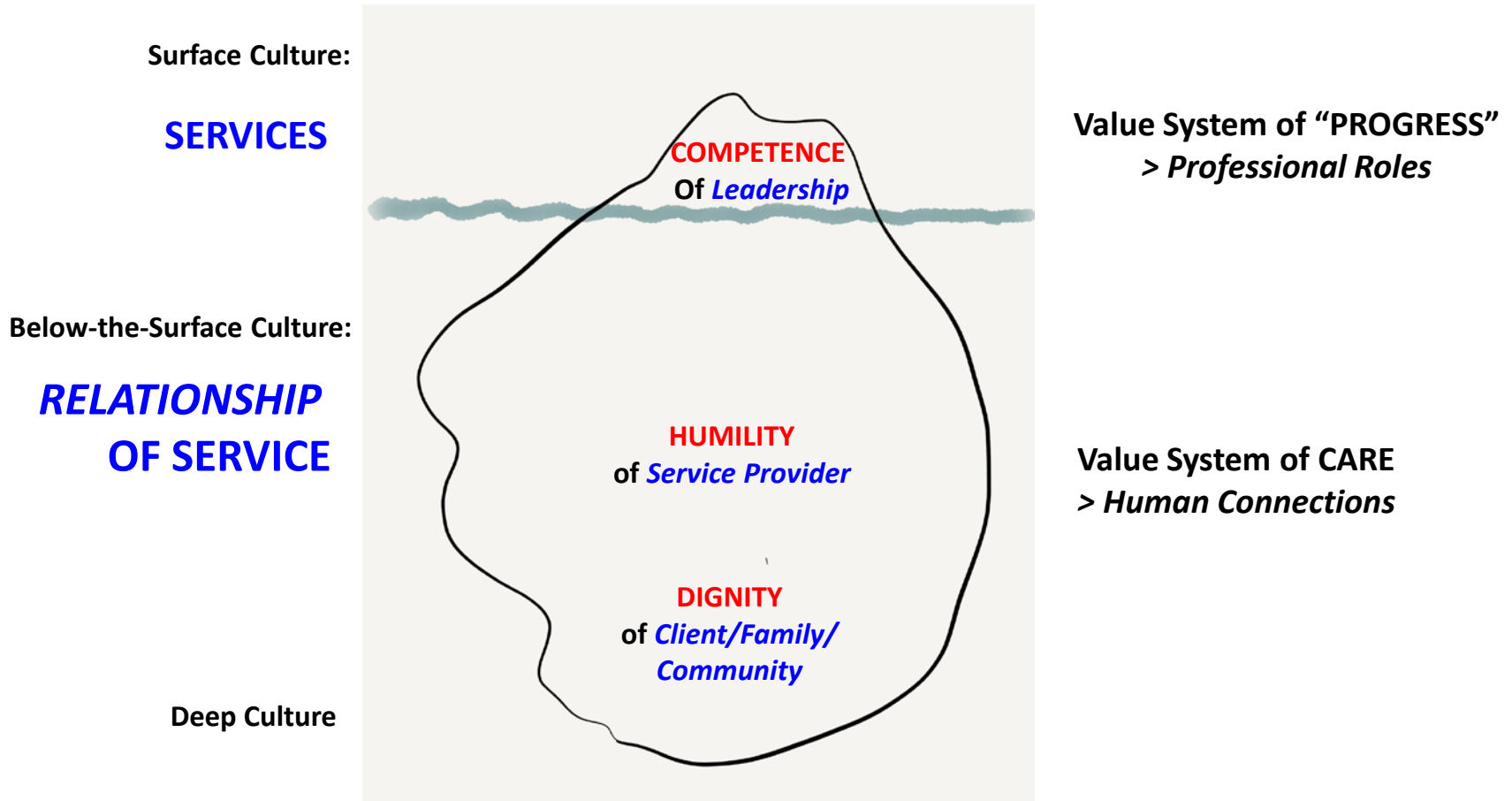
	Euro-American	Typical Latino
Medical decision-making	Patient Autonomy Informed Consent	<i>Family-based</i>
Communicating “bad news”	Truth-Telling	<i>“Protecting the patient”</i>
Advance directives	Self-Determination	<i>“Doctor knows best”</i>

Ethical Implications

Policies, procedures and practices that are beneficial for one culture might not be beneficial, or might be harmful to others.

A Roadmap for Service Providers

Model of *Cultural Wholeness*



Cultural Wholeness

CULTURAL COMPETENCE: “a set of congruent behaviors, attitudes, and policies that come together in a system, agency or among professionals and enable (them) to work *effectively* in cross-cultural situations.” Wikipedia
@ System/Organization

CULTURAL HUMILITY: “an ability to maintain an interpersonal stance that is other-oriented (or open to the other) in relation to aspects of *cultural identity* that are most important to the person.” Wikipedia
@ Service Provider

CULTURAL DIGNITY: “a stance that validates each person’s perspective, as a legitimate voice embedded in a set of socio-historical, environmental, spiritual and symbolic relations.” Silvia Austerlic
@ Client/Family/Community

Different Value Systems

**Value System of “Progress”
-Management Perspective-
@ SERVICES**

Authority, Competition,
Efficiency, Financial Success,
Order, Hierarchal Ability,
Informing, Managing,
Achievement, Predictability,
Problem Solving, Productivity,
Quality, and Charity

**Value System of Care
-Relational Perspective-
@ RELATIONSHIP OF SERVICE**

Acceptance, Balance, Being Present,
Choice, Commitment, Courage,
Creativity, Empathy, Intimacy,
Learning, Listening, Openness,
Personal Growth, Questioning,
Reflection, Trust, and Well-Being

WHAT'S IMPORTANT: Understanding and Working with Values Perspectives, by Kenton Hyatt & Cheryl De Ciantis

Serving as a *Culturally Empathetic Bridge*



From
Curative Care
“Getting Better”

To
Palliative & Hospice Care
“Dying Well”

Relationship of Service

Axiology of "Progress"		Axiology of Care
Helping	Fixing	Serving
Perceiving person as "weak," helped by the "strong."	Perceiving person as "broken"; their brokenness requires me to act.	Perceiving person as " whole ," which I see and trust.
Based on <i>inequality</i> of strength. It incurs debts. We may inadvertently take away more than we could ever give them.	A form of <i>judgment</i> that creates distance. Experience of difference.	Mutuality . We can only service that to which we are profoundly connected, that which we are willing to touch.
Experience of <i>strength</i> .	Experience of <i>mastery & expertise</i> .	Experience of mystery, surrender and awe .
Bases of <i>Curing</i>	Bases of <i>Curing</i>	Bases of Healing
Rachel Naomi Remen: <i>In service of Life</i> . Noetic Sciences Reviews, Spring 1996		

Walking the Talk of Cultural Humility

Starting point: not mastery of lists nor examination of the student's belief system; but a careful consideration of assumptions and beliefs embedded in care provider's own agenda for the clinical encounter

Most serious barrier: not lack of knowledge of the details; but service provider's failure to develop self-awareness and a respectful attitude towards diverse points of view

Barriers to Cultural Humility

- Stereotyping
- Judging
- Holding on to our agenda
- Unconscious biases
- Lack of mindfulness
- Disconnection from emotional/heart intelligence
- Thinking we know best

Cultivating Cultural Humility

Becoming a *Student* of the Patient

- 1. Listening Presence**
- 2. Relationship with Cultural Differences**
- 3. The Wisdom of Not Knowing**

Listening Presence

- *Intentional receptivity*
- “*Holding the space*” : makes room for what needs to emerge
- *Witnessing* : validates the other’s experience
- *Being with* : conveys company
- *Being there* : conveys support



Relationship with Cultural Differences

What is my relationship with **cultural differences**?

- How do I **notice** them?
- How do I **react** to them?
- How do I **manage** my reactions?
- How do my reactions **impact** my understanding of & communication with patients and families?
- How do I **find common ground**?
- How do I **negotiate care** with patients and families?

Mindset of *Not Knowing*

To explore cultural *below-the-surface factors* impacting pt's experience & pt-provider interaction:

- Engage from a place of respectful curiosity
- Pay non-judgmental attention
- Ability to put individual agendas aside
- Notice verbal and non-verbal communication
- Do not assume
- Ask open-ended questions
- Allow silence
- Be comfortable with ambiguity
- Include different opinions

Experiential Activity

- Acceptance of Identity
 - Recognition
- Acknowledgment
 - Inclusion
 - Safety
 - Fairness
- Independence
- Understanding
- Benefit of the Doubt
 - Accountability

Essential Elements of Dignity

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Cultural Humility for Service Providers

Recommendations at the EOL

- To “meet people where they are” and walk together through *shifts* in goals of care.
- To meet the unique needs and wishes of each patient by providing *choices* at the EOL.
- To “hold the hands” of patient & family as goals of care shift, so *cultural values* and the *perception of care* are not lost, and they can experience “quality of life” in their own terms.

Intercultural Dignity

Recommendations at the EOL

Taking into consideration patient, family and community's perspective, by providing “safe and brave context” for “delicate conversations”:

- To learn complex information (that might trigger *natural anticipatory grief responses*) in a compassionate culturally sensitive environment.
- To understand *treatment options* (benefits & burdens) and their *consequences*.
- To make *medical decisions*, taking into consideration one's values, needs and wishes.

Thank You!

More about my Work

Cultural Humility and Compassionate Presence
at the End of Life (Markkula Center for
Applied Ethics, Santa Clara University)

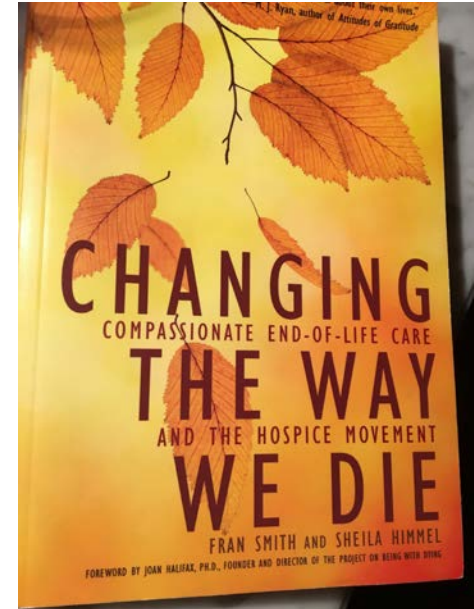
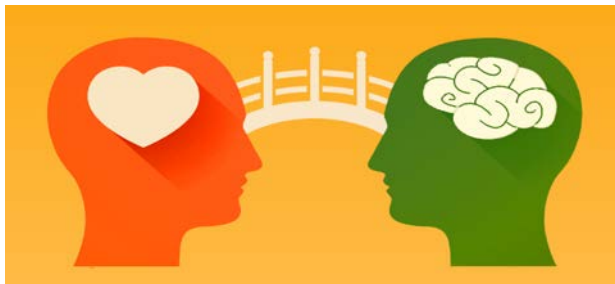
<https://www.scu.edu/ethics/focus-areas/bioethics/resources/culturally-competent-care/from-chronic-to-critical/cultural-humilitycompassionate-presence/>

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Cultural Revolutions
(Chapter Thirteen)