

CULTURAL COMPETENCE CONSIDERATIONS IN HUMAN SUBJECTS RESEARCH

Maria Davila, MD, MAB, CCRC, CIP- Associate Director

Emory IRB



Institutional Review Board Research Administration

CONTENTS

- Definitions
- Illustrative video
- Beyond the tip of the iceberg
- Cultural Competence for Researchers
- Why is Cultural Competence important in Research?
- How can we protect participants rights and welfare?
- How can we prevent putting participants in situations of increased risk?
- How can we prevent putting the burden of adaptation in participants?
- What is there for me and my study?
- Sources and references

What is cultural competence?

The ability to work effectively across cultures in a way that acknowledges and respects the culture of the person or organization being served.

Cultural Competence involves treating people in a way that makes them feel that their ideas, values, traditions, or behaviors are acknowledged and respected

J.H. Hanley (1999)-<u>Beyond the tip of the iceberg:</u> <u>Five Stages toward cultural competence</u>

Jowsey BMC Medical Education (2019)





Citation for the electronic image: Waitemata District Health Board. (2019). Cultural Competence Continuum (Online image).

Cultural destructivenesscharacterized by attitudes, policies, structures, and practices within a system or organization that are destructive to a cultural group.

Cultural incapacity-Disproportionate allocation of resources to certain groups; lowered expectations; discriminatory practices, unchallenged stereotypical beliefs.

Cultural blindness- Discomfort in noting difference; beliefs / actions that assume world is fair and achievement is based on merit; we treat everyone the same: this approach ignores cultural strengths. The belief that methods used by the dominant culture are universally applicable can lead to implicit or explicit exclusion of ethnic minority communities

Cultural pre-competence- Delegate diversity work to others, e.g. cultural programs asked to be lead by those of that background; quick fix, packaged short-term programs; a false sense of accomplishment; inconsistent policies and practices; practitioners are sensitive to minority issues but these are not an organizational priority

- Cultural competence- Advocacy: on-going education of self and others; support, modeling, and risk-taking behaviors; a vision that reflects multi-culturalism, values diversity and views it as an asset: evidence of continuing attempts to accommodate cultural change; careful attention to the dynamics of difference, realizing that equal access is not equal treatment.
- Cultural proficiency- Interdependence; personal change and transformation; alliance for groups other than one's own; adding to knowledge-base by conducting research; developing new therapeutic approaches based on cultural considerations; follow-through social responsibility to fight social discrimination and advocate for social diversity.

Reference: Georgetown University Center for Child and Human Development- National Center for Cultural Compentence<u>https://nccc.georgetown.edu/video-infusing-clc/continuum.pdf</u>



Reference: <u>https://www.youtube.com/watch?v=dNLtAj0wy6l</u>

BEYOND THE TIP OF THE ICEBERG

- Culture can be compared to an iceberg, because so much goes undetected. So that within our lives and work it is often ignored. The influence of culture on the elements of communication need to be explicitly explored rather than taken for granted or ignored.
- This out- of -awareness part of culture has been termed "deep culture" although it does include some elements of folk culture.
- Deep culture includes elements such as the definition of sin, concept of justice, word ethic, eye behavior, definition of insanity, approaches to problem solving, fiscal expression, and approach to interpersonal relationships.

Gary Weaver (1986)

Surface Culture

Language Arts, Literature Religion, Music, Dress, Dance, Sports, Cooking

Folk Culture

Awareness Level boundary

NOTIONS OF MODESTY, CONCEPTS OF BEAUTY, EDUCATION, CHILD RAISING, RULES OF DESCENT, COSMOLOGY, RELATIONSHIP TO THINGS, ANIMALS & PLANTS, COURTSHIP PRACTICES, CONCEPT OF JUSTICE, MOTIVATION TO WORK, CRITERIA FOR LEADERSHIP, DECISION MAKING PROCESSES, DEITIES, DEATH, IDEAS OF CLEANLINESS, LOCUS OF CONTROL, THEORY OF DISEASE, PHYSICAL SPACE, DEFINITION OF SANITY, FRIENDSHIP, LOVE, MURDER, LIFE, GENDER, FACIAL EXPRESSIONS, ROLES IN RELATION TO STATUS BY AGE, GENDER, CLASS, KINSHIP, OCCUPATION, RELIGION, CONVERSATIONAL PATTERNS IN VARIOUS SOCIAL CONTEXTS, CONCEPTION OF TIME & SPACE, PREFERENCES FOR COMPETITION, COOPERATION, INDIVIDUALISM OR GROUP NORMS, SIN, GRACE, NOTION OF ADULTHOOD, NOTION OF LOGIC AND VALIDITY, PHYSICAL SPACE ARRANGEMENTS, LIFE ODORS, HANDLING OF EMOTIONS, ACCEPTANCE OF FRUSTRATION OR PAIN, CONCEPT OF FAITH

CULTURAL COMPETENCE FOR RESEARCHERS

- Uni-cultural perspectives: assume that concepts and explanations of relationships between concepts are universal
 - Prevent investigators to be open to other perspectives
 - Researchers impose their beliefs, values and patterns of behavior upon cultures others than their own
- Uni-cultural perspectives could create invalid research data

Reference: Papadopoulos and Lees, Developing culturally component researchers

CULTURAL COMPETENCE FOR RESEARCHERS





CULTURAL COMPETENCE FOR RESEARCHERS



CULTURAL COMPETENCE FOR RESEARCHERS



CULTURAL COMPETENCE FOR RESEARCHERS



CULTURAL COMPETENCE FOR RESEARCHERS





Ę

WHY IS CULTURAL COMPETENCE IMPORTANT FOR RESEARCH?

- The IRB regulations are based on three principles from the Belmont Report: Justice, Beneficence and Respect for Persons
 - Justice: that benefits and burdens are distributed fairly
 - Beneficence: ameliorating harm as much as possible
 - Respect for Persons: that potential participants are adequately informed before deciding to participate in a research study



WHY IS CULTURAL COMPETENCE IMPORTANT FOR RESEARCH?

Justice: how can we ascertain that we are distributing benefits adequately if we are not educating ourselves about the needs of other cultures different from ours?

Beneficence: are we ensuring we are ameliorating harm if we do not know the cultural needs of others?

- This may affect how funds are invested for research
- What populations are being included/excluded from research that may receive some benefit?

- This could manifest as an unintended action that may put the participant at increased harm
- For example, not considering people's beliefs on taking medication (or the basic language barriers) may affect their compliance to follow our directions
- · Certain cultures do not challenge their doctors

Respect for Persons: how can we ensure that the consent process is truly adequate if we do not have a basic cultural awareness of the person in front of us?

- Starts with the IC document itself, who is helping us with the consent process and our general approach to invite people to participate in research
- This will affect the person decision to participate in research, even if it is of some benefit for them or their population

WHY IS CULTURAL COMPETENCE IMPORTANT FOR RESEARCH?

- Because it is a requirement, not only by the IRB but also by federal oversight offices
 - DHHS Department of Minority Health produced standard for Culturally and Linguistically appropriate services- healthcare organizations should use a variety of methods to collect demographic data and become informed about ethical and cultural needs
 - <u>https://thinkculturalhealth.hhs.gov/clas</u>

WHY IS CULTURAL COMPETENCE IMPORTANT FOR RESEARCH?

- Because it is ethically relevant. We are asking a lot from participants. Don't we have an obligation to ensure their well-being?
- We all have a responsibility to develop a deep understanding of the participants we serve to ensure that:
 - We are protecting their rights and welfare
 - We are not putting them in situations of increased risk
 - We are not putting the burden of adaptation in our participants

HOW CAN WE PROTECT PARTICIPANTS RIGHTS AND WELFARE?

- Informed consent process
 - How many times do you encounter a participant who tells you they are fluent in English but you do not ask them questions during the consent process to ensure this is correct?
 - This is not to say a participant is being dishonest: there is "stigma" for people who live in this country who are not fluent in English
 - It could be that the participants believes their basic conversational English is enough to understand a complex Phase 2 cancer study
 - Is your team always using interpreters for consents, and translating consents as much as possible?

- If we do not understand our participants cultural differences, we may not be effective in keeping them safe:
 - A subject may not take their medication because they think that once a day is enough or just to take the medicine when they feel pain
 - Some cultures identify being sick with feeling sick. A lot of diseases do not have obvious symptoms. Taking additional time to explain consequences and providing additional information may help.
 - A subject may want to do a ritual in their hospital room, throwing a sugary liquid around while singing a hymn
 - We should respect people's different beliefs and try to accommodate requests if it will help ensure participants trust in their medical providers, including research staff

HOW CAN WE PREVENT PUTTING PARTICIPANTS IN SITUATIONS OF INCREASED RISK?

HOW CAN WE PREVENT PUTTING THE BURDEN OF ADAPTATION IN PARTICIPANTS?

Understanding language disparities and addressing them	 Ask questions during the consent process to assess LEP levels. Suggest interpreters in a compassionate way
Providing additional information, as needed, to participants to help them navigate the health care environments	 The clinic environment could be intimidating even for people born in the US!
Learning about disparities in health outcomes	Will help with ameliorating health burden to people from other cultures different to mine
Ensuring all members of team have a basic understanding of cultural differences, including medical students	 It is not enough to rely on "cultural profiles" as they can cause generalizations and potential biases towards our participants

HOW CAN WE PREVENT PUTTING THE BURDEN OF ADAPTATION IN PARTICIPANTS?

Creating distance and stereotypingundermines trust that is essential to competent care

Cultural checklist example and nurses

Move out of comfort zone and explore own issues with different cultures

<u>https://implicit.harvard.edu/implicit/takeatest.html</u>

Challenge your leaders to ensure everyone is culturally aware and working towards cultural competence!

WHAT THERE IS FOR ME AND MY STUDY?

Culturally incompetent research is bad researchcould be affected by researchers unilateral view of culture

Besides the satisfaction of diminishing the disparity gap, you are also helping your study by having more engaged, responsive subjects who may respond better to your study requirements

Remember: the important point is to be open to other cultures views, and to be able to recognize our own implicit biases. Don't put your own ideas of how "things should be" on others and help your subjects in their study participation journey.

SOURCES AND REFERENCES

- Online assessment: <u>https://nccc.georgetown.edu/assessmen</u> <u>ts/</u>
- Cases: <u>https://www.scu.edu/ethics/focus-</u> <u>areas/bioethics/resources/cases/cases-</u> <u>on-culturally-competent-care/</u>
- Cultural Competence in Research (Annotated Bibliography):<u>https://catalyst.harvard.e</u> <u>du/pdf/diversity/CCR-annotated-</u> <u>bibliography-10-12-10ver2-FINAL.pdf</u>

THANKS

ITR

IDE

D

NIA-T-

Additional questions?

BELIEF

- Contact me at maria.davila@emory.edu
- Contact the IRB office at <u>irb@emory.edu</u>