CARE: A Model for the Integration of Cultural Humility into Human Subjects Research

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Dr. Loue has been privileged to conduct research in Laos, Russia, Romania, Tajikistan, and Uganda, and to engage with audiences on issues including the ethical conduct of research, professional development, and diversity in Canada, Chile, Colombia, Kazakhstan, Mexico, Romania, Russia, Spain, Switzerland, Tajikistan, and Vietnam. She has mentored U.S.-based and international graduate students, postdoctoral fellows, and faculty for more than 20 years.

Dr. Loue's past research in both the domestic and international contexts has focused on HIV risk and prevention, severe mental illness, family violence, and research ethics. Her current research addresses the interplay between religion, society, and bioethics; the integration of cultural humility into clinical care and research settings; and past and current formulations of eugenics. She has authored or edited more than 30 books and has authored/co-authored more than 100 peer-reviewed journal articles.

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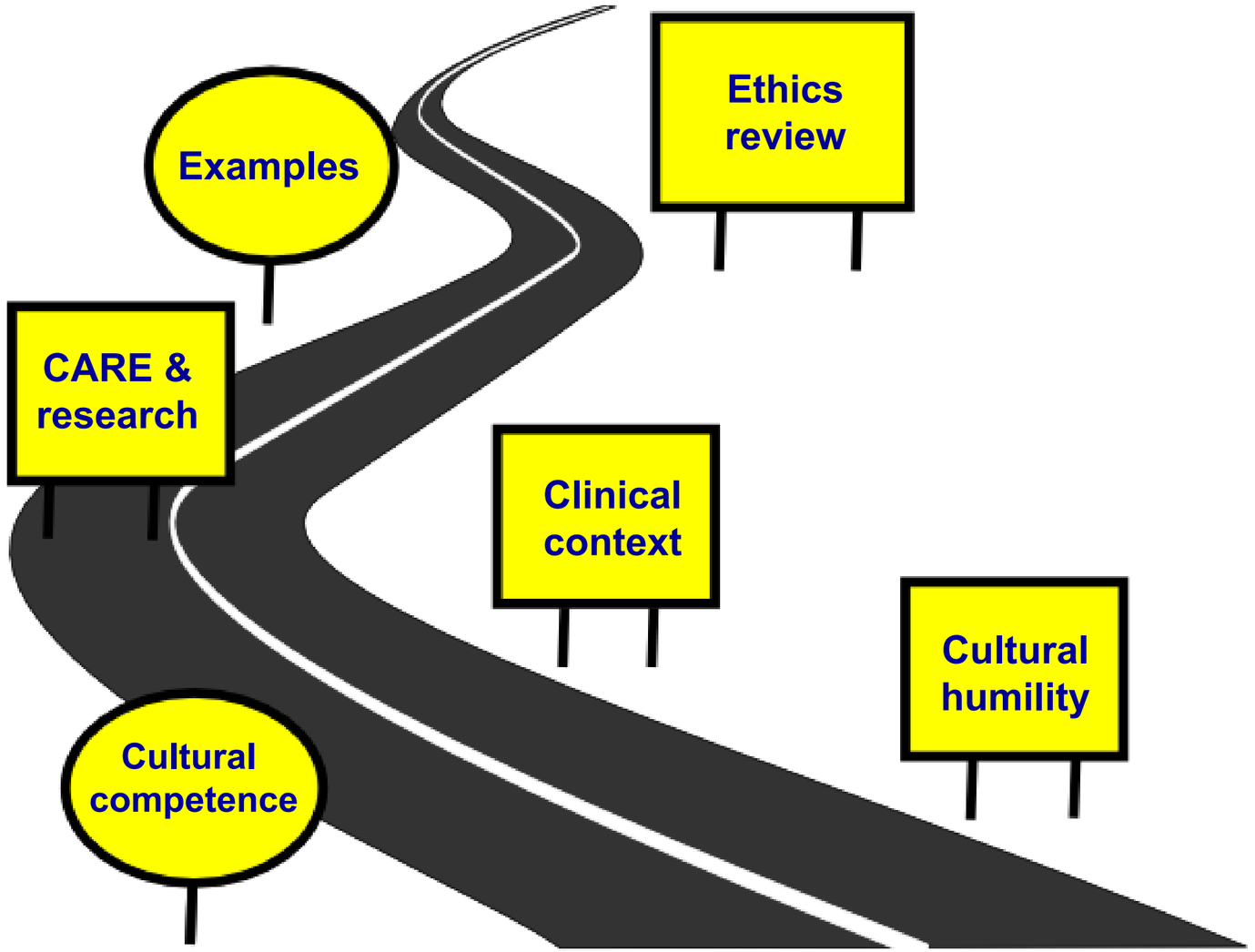
Learning Objectives

1. Distinguish between cultural competence and cultural humility
2. Explain how cultural humility can be integrated into human subjects research
3. Identify strategies for the development and application of cultural humility in research


Examples
Ethics review
CARE & research
Clinical context
Cultural humility
Cultural competence

Cultural competence

- Provides knowledge base about different groups based on identifiable or identified characteristics or qualities
- Allows individuals to monitor their own explicit biases and behaviors
- Offers promise of mastery

Underlying assumptions of cultural competence

- “Problem” of cultural incompetence due to ignorance or prejudice; fails to consider systemic issues
- Mastery of a culture is possible
- Culture is static
- Interaction and mutual evolution of majority and minority groups and cultures irrelevant
- Does not lead to stereotypes and responses to stereotypes
- Diversity is a challenge only between non-Hispanic Whites & URMs
- Only one salient factor, e.g., race, ethnicity, sex, gender
- Members of identified group are “culturally competent” with respect to that group
- Assumed/projected identity=actual self-identity
- Knowledge is not constructed

What is cultural humility?

- Basic assumption: in every interaction there is something that we do not know or understand
- Focuses on development of critical consciousness to change attitudes and not only knowledge/explicit behaviors
- Requires lifelong self-reflection, self-critique, learning, and transformation
- Requires active engagement, commitment to reciprocity
- Requires exercise of humility in every encounter to bring into balance existing power imbalances (Tervalon & Murray-García, 1998)

Cultural humility recognizes that . . .

- Culture changes over time
- Culture changes over time at the group/ and societal levels
- Culture changes over time at the interactional level
- Change at each level may occur at different rates
- A successful outcome requires appropriate mechanisms of interaction and balance between individuals, groups, and the larger society

Cultural humility: Key elements

- Active listening
- Bidirectional cultural immersion
- Collaboration
- Consideration of other perspectives
- Context-specific
- Egolessness
- Emphasis on egoless practice and not knowing
- Ethical engagement
- Flexibility of negotiation
- Interrogation of one's own biases and assumptions

- Interrogation of one's own biases and assumptions
- Intersectionality
- Lifelong process
- Ongoing critical reflection
- Openness to new ideas
- Other-focused
- Realignment of power relations/balance
- Self-awareness
- Self-evaluation
- Self-questioning and self-critique
- Supportive interaction

Sources: Chang, Simon, & Dong, 2012; Clark et al., 2011; Coulehan, 2006; Cruess, Cruess, & Steinert, 2010; Foronda, et al., 2016; Foster, 2009; Hook et al., 2013; Isaacson, 2014; Minkler, 2012; Ortega & Faller, 2011; Rivera & Grauf-Grounds, 2020; Tervalon & Murray-García, 1998; Thurber, 2020; Yancu & Farmer, 2017

Cultural competence & cultural humility compared

Cultural Competence

- Viewed as discrete endpoint
- Focuses on substantive/content issues, (e.g., health beliefs)
- Learning is informative
- Often results in stereotyping
- Often creates false sense of security from “knowing”

Cultural humility

- Process as key element
- Requires continual self-reflection and self-critique
- Requires realignment of power imbalances
- Learning is transformative
- Acknowledges each participant in interaction as co-learner and expert with respect to experience

Cultural humility in the clinical context

- **5 Rs**: **R**eflection, **R**espect, **R**egard, **R**elevance, and **R**esiliency (Masters et al., 2019)
- **QIAN** (Humbleness): self-**Q**uestioning and critique, bidirectional cultural **I**mmersion, mutually **A**ctive listening, and flexible **N**egotiation. (Chang et al., 2012)
- **ORCA**—**O**penness, **R**espect, **C**uriosity, and **A**ccountability (Graf-Grounds & Rivera, 2020)

CARE: A new model for integrating cultural humility in research

- **C**uriosity
- **A**ttentiveness
- **R**espect and **R**esponsiveness
- **E**mbodiment

Curiosity

- Integral to science and scientific research (Jirout, 2020)
- Recognition that something is unknown
- Sense of wonder (Hunter, 2015)
- Acknowledgement of nuance and ambiguity (Jirout & Klahr, 2012; Metz, 2004; van Schijndel et al., 2018)

Attentiveness

- “the state of being awake, alert and actively paying attention to a stimulus” (psychologydictionary.org)
- “the quality of listening or watching carefully and with interest” (Oxford Learner Dictionary)
- “Attention is the rarest and purest form of generosity” (Simone Weil, *Gravity and Grace*)
- Focus on multiple dimensions and the whole (see Wilson & Gochyyev, 2020)
- Active listening through verbal and nonverbal behaviors

Respect

- I-Thou (Buber)
- Willingness to engage as equals
- Listening to understand rather than to respond

Responsiveness

- Grounded in ongoing, shifting confluence of knowledge, understanding, awareness of self and triggers
- Respond vs. react
- Attunement

Embodiment

- Attunement to person, context, self
- Inherently relational, involving relationships between persons and between persons and their environments (Leder, 1992)
- Our neural systems recreate what others do and feel
  - People model others' behavior or mental states as intentional experiences : "embodied simulation" (Gallese, 2006).
- Bodily resonance:
  - An intuitive understanding of others that occurs in ongoing interactions, often on a pre-reflective level
  - A process of mutual modifications of bodily and emotional states that takes place as a result of bodily presence (Engelsrud, Ølen, and Nordtug, 2019, 919).

The development of embodiment requires . . .

- Close attention to body
- Individual assessment: is what I am doing congruent with what I am feeling?
  - Focusing associated with higher levels of empathy (Nasello and Triffaux, 2020).
- Practice
  - Puppetry pedagogy (Tsaplina, 2020)
  - Drama (de Carvalho Filho et al., 2020)
  - Virtual reality training (Li, Ducleroir, Stollmen, and Wood, 2021)

To develop and manifest cultural humility . . .

Stay Centered, Remain in Balance

(SCRiB)

Cambodian Pre-exposure Prophylaxis Trial

- Trial designed to test safety and efficacy of antiretroviral drug tenofovir disoproxil fumarate to prevent HIV
- Is 1 pill/day safe for HIV- people? Does it prevent HIV?
- 1st large-scale CT in Cambodia, began 2003
- 1st PrEP trial to be canceled (2004)
- 2005: 3 PrEP trials canceled
  - Cameroon: lack of participant education
  - Malawi & Nigeria: concerns re: lab procedures, availability of drug on open market

Controversies in Cambodia PrEP trial

- Researcher focus on adherence to ethical principles
  - Rights conceived of as universal
- “Postcolonial bioethics”: concerned with relations (Grant, 2016)
  - Focus on unequal relations between researchers, funders, regulatory bodies and participant community
  - Trial conceived of as binary: foreign investigators acting on Cambodia sex workers; Cambodian collaborators largely unseen
  - Implication that well-being of Cambodians to be exploited for the benefit of non-Cambodians

Would cultural humility have made a difference? Might use of the CARE model have helped to manifest cultural humility here?

- Unknowns
  - Underlying researcher /IRB implicit assumptions about sex workers, Cambodians
  - Impact/effect of Womyn's Agenda for Change refusal to sign 2003 "anti-prostitution" pledge required by US govt for receipt of funds under President's Emergency Plan for AIDS Relief (PEPFAR); issue of identity?
- Increased engagement and collaboration with relevant communities
- Increased understanding of and sensitivity to local context
  - Lack of safety net for sex workers and their families if adverse events
  - History of colonialism
  - Local portrayal of sex workers as victims in need of rescue, trafficking vs. choice

CAFÉ trial, University of Minnesota and Dan Markingson

- 26-year-old male, 1st psychotic break 2003
- Involuntarily hospitalized; court-appointed psychologist concluded “gross impairment of judgment, behavior, capacity to recognize reality, capacity to reason or understand”
- Stephen Olson, MD– both PI Of AstraZeneca-funded double-blind randomized trial to compare quetiapine, olanzapine, risperidone for first episode schizophrenia AND Markingson’s psychiatrist
- Markingson signed ICF without mother or participant advocate present
- Markingson to be involuntarily committed if failed to follow psychiatrist’s regimen

Markingson's death

- Markingson transferred to halfway house
- Continued to deteriorate
- Study team and university officials essentially nonresponsive to mother's concerns
- Markingson suicide May 8, 2004
- Only drug in system was study drug Quetiapine
- Audit by Minnesota state found deficiencies in IRB review, conflict of interest

Reviewing for curiosity

- How and to what extent has the research team familiarized itself with the social, cultural, economic, and historical context of the proposed participants/participant community?

- How and to what extent do research procedures facilitate an examination of team members' biases and values and their potential impact on the research participants and the course of the research?

Reviewing for attentiveness

- What stereotypes or assumptions about the study site and/or participants do the researchers bring to the endeavor?
- How have individual research team members who will have contact with participants or analyze data been trained to interact with participants and/or examine how their assumptions may impact their data interpretation?

Reviewing for respect and responsiveness

- To what extent, in what way, and for how long has the research team engaged with the prospective participant community?
- What mechanisms have been put in place to reduce the power imbalance between the researcher and research participants and/or the participant community?
- Are the research protections and levels of participant remuneration responsive to participants' concerns, as well as federal regulations and international guidelines?
- Are representatives of the participant community consulted for their input? In other words, do they have a seat at the table?

Reviewing for embodiment

- Have the researchers considered the potential implications for participants because of their contact with team members, (e.g., if there may be political or social repercussions from contact with foreigners?) How will they manage this potential?
- Have the researchers developed adequate measures to protect the identity of the participants?
- Have the members of the research team designed the study in such a way as to be sensitive to local customs and mores relating to personal space and interpersonal communication?

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MDPI

Review

The CARE (Curiosity, Attentiveness, Respect and Responsiveness, and Embodiment) Model: Operationalizing Cultural Humility in the Conduct of Clinical Research

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Abstract: Cultural competence training has been criticized for reinforcing existing stereotypes, ignoring intersectionality and inadvertently marginalizing some individuals and groups. In contrast, cultural humility offers the possibility of transformational learning, requiring individuals to pursue a lifelong course of self-examination. This approach makes authentic engagement with others possible. We review the premises underlying cultural competence and cultural humility, as well as proposed models for the integration of cultural humility into the clinical context. We propose a new model for the integration of cultural humility into clinical research: CARE, signifying Curiosity, Attentiveness, Respect and Responsiveness, and Embodiment. We conclude that the concept of cultural humility can be integrated into the conduct of clinical research.

Keywords: cultural competence; cultural humility; clinical research

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1. Introduction

The concept of cultural competence first gained prominence in the United States during the 1980s as an approach to addressing diversity and inequalities [1,2]. It was seen as a potential strategy that could be used to bridge differences that existed between middle-class, often white biomedical clinicians and their patients, whose language and experiences frequently differed from those of their clinicians [3]. Cultural competence pedagogies often assumed that difficulties bridging such gaps were attributable to a lack of knowledge on the part of the clinicians and that these gaps could be remedied through the provision of information about other cultural groups [4]. As such, cultural competence was seen as a tool that would permit an individual or system to better address the needs of their patients or clients who were perceived to be different in some way.

Early definitions of cultural competence tended to view cultures as static and monolithic, reifying and essentializing groups [1,2,5–7] rather than recognizing that culture is actively produced through a social process [8]. More recent definitions focus not only on knowledge, but also on attitudes and behaviors [9,10]. This tripartite approach has been criticized as both reductionistic and as reproducing the power dynamic in which the provider is assumed to be the holder of knowledge [1,4].

Later scholarship has focused on various concepts seeking to bridge barriers in communication and understanding between individuals: cultural sensitivity, intercultural communication, and cultural humility [11–13]. We focus here on the concept of cultural humility, its key components, and its use in the context of clinical encounters. Finally, we propose a new model that permits the integration of cultural humility into the conduct of clinical research.

2. Cultural Humility

Unlike cultural competence which is encounter-based, cultural humility is relationship-based. Tervalon and Murray-García, the originators of the concept, defined it as follows:

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Thank You

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Questions

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