

Conducting Culturally Humble Rehabilitation Research

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Conducting Culturally Humble Rehabilitation Research

*RRTC on Developing
Strategies to Foster
Community Integration and
Participation for Individuals
With Traumatic Brain Injury*

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Importance

- 1/3 of U.S. citizens are non-European
- Disproportionately higher rates of disability among minorities
- African-Americans and Hispanics over-represented in stroke, SCI, and TBI

Cultural Competence in Health Care

“the ability of systems to provide care to patients with diverse values, beliefs and behaviors, including tailoring delivery to meet patients’ social, cultural, and linguistic needs”

Bettencourt et al., 2002

Components of Multicultural Competency

- Attitudes/beliefs
- Knowledge
- Skills

Cultural Competence



- Combination of
 - Body of knowledge
 - Body of belief
 - Body of behavior

Cultural Competence

- Best defined not as a discrete endpoint but as a commitment and active engagement in a lifelong process that individuals enter into on an ongoing basis with patients, communities, colleagues, and with themselves

- Process of
 - Having an accurate view of self AND
 - Able to maintain an interpersonal stance that is other-oriented rather than self-focused

Cultural Humility



- Characterized by:
 - Lifelong commitment to self-evaluation and self-critique
 - Desire to fix power imbalances
 - Development of partnerships with people and groups who advocate for others

Cultural Humility



- No need to master health (or other) beliefs of a particular group

Multiple Cultural Roles



- Mexican-American
- male
- father
- husband
- Catholic
- mechanic
- night-school student
- resident of Los Angeles

Cultural Humility in Research

- Awareness of your own patterns of beliefs, including stereotypes
- Openness to hearing participants' lived experience
- Participant as expert of their own lives/ cultures
- Stepping away from past experience and knowledge when approaching new participant or group

Implementation of Culturally Humble Research

ADDRESSING CULTURE AND LANGUAGE TO IMPROVE DATA QUALITY

What is Culture?



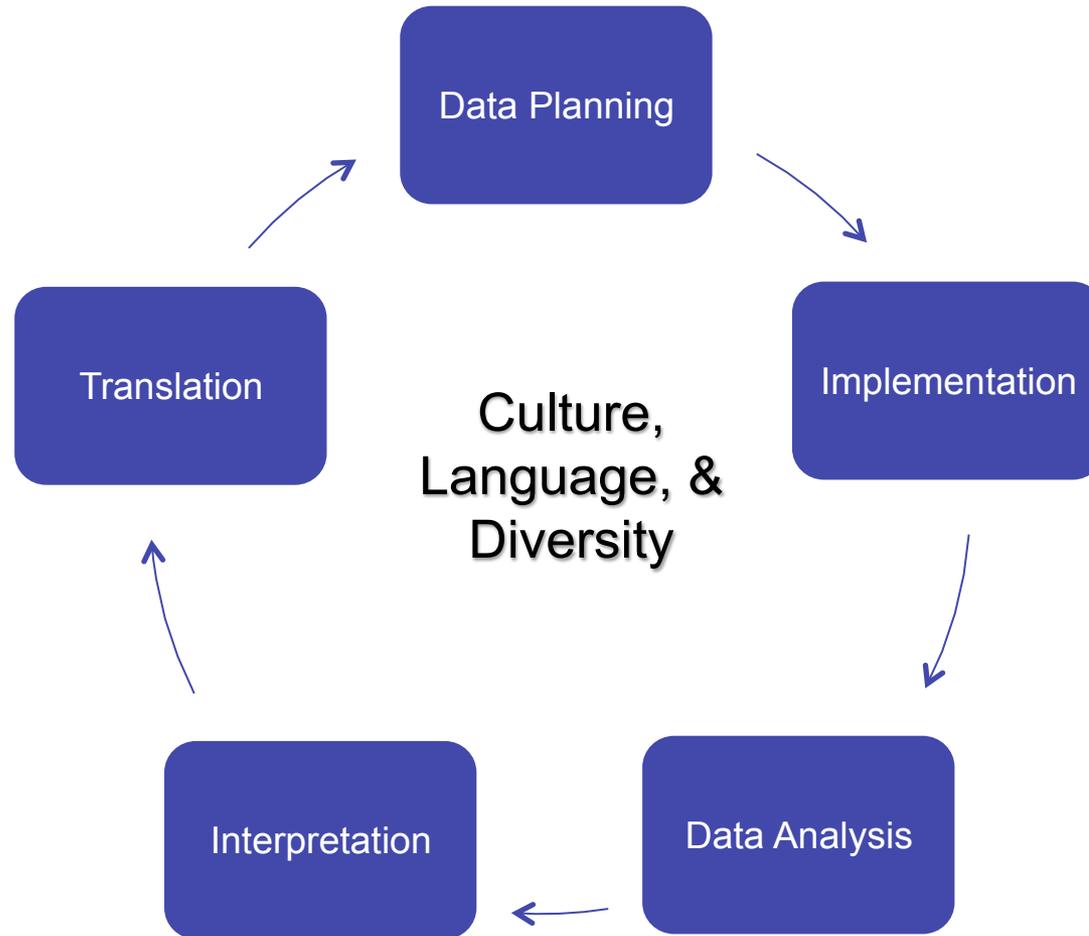
- Diversity consists of many dimensions:
 - Internal Dimensions
 - Examples: Age, Race/Ethnicity, Physical Abilities/Qualities
 - Other Dimensions
 - Examples: Religious beliefs, Marital status, Education

“not research about another culture, but research done with a raised consciousness concerning the impact of culture on the person and/or phenomena being studied, on the research process itself, and on the researcher.”

Henderson et al., 1992

- “Being aware of and appropriately responding to the ways in which cultural factors and cultural differences can influence all stages of the research process, including:
 1. What we investigate
 2. How we investigate
 3. How we analyze and interpret our findings.”

What is Culturally Competent Research?



Provide Training and Resources to assess:

1. Cultural Awareness
2. Cultural Knowledge
3. Cultural Sensitivity
4. Cultural Competence

(Papadopoulos & Lees, 2002)

Language Barriers in Research

- Illiteracy and Health Illiteracy
- Limited-English proficiency
- Lack of translators
- Unavailability of validated measures in target population's language
- Lack of normative data
- Response set bias



What is Linguistic Competence?

- Providing readily available, culturally appropriate oral and written language services to limited English proficiency (LEP) members through such means as bilingual/bicultural staff, trained medical interpreters, and qualified translators.

AHRQ, 2003

Effective Communication Techniques

- Establish rapport
- Pay attention to nonverbal cues
- Use language of participants
- “Person before disability” language
- Use cultural terms accepted by participants
- Avoid stereotyping
- Ask culturally sensitive questions
- Look for and respect cultural differences

Best Practices When Using Interpreters

- Speak directly to the participant
- Ask interpreter to not paraphrase
- Introduce everyone
- Be sensitive and pause often
- Give interpreter time to translate
- Avoid technical jargon
- Avoid side conversation with interpreter in front of participant

Cultural Barriers in Research

- Underrepresentation of certain groups:
 - Racial/ethnic minorities
 - Women
 - Children and Elderly
- Socioeconomic status
- Rural settings
- Acculturation and Immigration Experience
- Inclusion of diverse research team
- Lack of familiarity with target population
- Culturally Insensitive Data Analysis and Interpretation

Culturally Competent Recruitment Considerations

- Address issues of confidentiality
- Include community members throughout the research process
- Appropriate compensation and no coercion
- Address issues of transportation and child-care barriers
- Culturally Competent Interviewers
 - Racial/ethnic makeup
 - Competence and experience
 - Bilingual/bicultural Staff
 - Understand cultural factors influencing participation



Informed Consent Process



- Participation is voluntary
- Limit use of medical or technical jargon
- Address confidentiality concerns
- Be honest about benefits and costs

Informed Consent Process

- Assess Literacy and level of comprehension
- Language of consent
- Knowing who should or should not sign
- The decision to consent may be a family decision
- Respecting cultural and gender role norms

Culturally Competent Retention Considerations

- Transportation and child-care barriers may still exist
- Accessibility of research setting must still be considered
- Use frequent and individualized contacts and personal touches
- Maintain contact information on family and friends
- Use various contact methods (e.g. texting, email, social media)

Implementation of Culturally Humble Research

CULTURALLY HUMBLE INTERVENTION RESEARCH

General Considerations in Intervention Research



- Research versus Clinical Care
 - Suspicion of research
 - Transparency regarding all aspects of project, including use of information and compensation
- Flexible scheduling
- Communication preferences

Benefits of Home Setting



- Fosters cultural humility
- Indicates respect for participant and their environment
- Enables researcher to understand the lived experience of participants
- Allows intervention to be tailored to the home environment, promoting generalizability
- Reduces transportation issues

General Considerations in Home Settings



- Presence and involvement of others in the home
- Other questions and concerns from participant and others in the home
 - Accessing resources and care
- Logistical

Assessment and Treatment Issues in Home Settings



- Privacy and Confidentiality
 - Psychiatric history
 - Alcohol and Substance Use
 - Limitations on confidentiality
- Communication with family members
 - Language
 - Relationship to participant

Assessment and Treatment Issues in Home Settings



- “Control” of the environment
 - Distractions
 - Atypical settings
- Hospitality
- Family stressors
 - Financial
 - Medical, Vocational, Social
 - Stability of residence

Intervention to Improve Functional Memory



- Middle-aged African American man living with elderly mother following discharge from rehabilitation
- Goal: improving independence with medication management
- Strategy: training in use of pillbox

Intervention to Improve Functional Memory



- Implementation: Mother's reluctance to give up control of medication management
 - Beliefs about her role as mother and caregiver for son
 - Skepticism and failure to achieve “buy in” regarding the project
- Lessons learned:
 - Importance of establishing family support
 - Reconciling her beliefs regarding her role as mother and family matriarch with rehabilitation goals of increasing independence

Intervention to Improve Functional Memory



- Middle-aged African American man returning to live in the community in which he was raised
- Goal: improving navigation of community
- Strategy: in vivo practice of routes and use of landmarks in the community, with therapist support

Intervention to Improve Functional Memory



- Implementation: beliefs about how others in the community perceived him
 - Worry that he would be perceived as an “easy target” if seen with therapists out in the community
- Lessons learned:
 - Understand participant's broader community
 - Appreciate concerns regarding security
 - Role of injury etiology: assaulted by unknown persons

Intervention to Improve Functional Memory



- Young adult Hispanic male living with mother following rehabilitation
- Goal: remembering to tell mother when he is leaving the house, and where he is going
- Strategy: incorporate use of reminder notes as part of routine when leaving the house

Intervention to Improve Functional Memory



- Implementation: concerns that mother is controlling him
 - Important to be seen and treated as a man
 - Experienced several losses that impacted view of self: unable to work; unable to live independently; mother assumed childcare responsibilities for his young children
 - Significant cognitive and behavioral issues

Intervention to Improve Functional Memory



- Lessons learned:
 - Importance of being viewed as a man, to family and to others in community
 - How neurobehavioral sequelae impacted sense of self as a man
 - Incorporate aspects that would positively impact his sense of self and control into strategy development

Other examples

- Social communication intervention: flexibility of communication
 - Relationship to the other person
 - Setting/situation
 - What is “normal”?
- Research priorities versus priorities of participants

Key Messages

- Conducting culturally humble research requires commitment, self-reflection, and openness.
- Treat participant as the “expert” on his or her own life and experiences.
- Culture is more than race/ethnicity.
- Every aspect of research, from recruitment to translation, can be impacted by culture.
- Partner with research staff from different cultural backgrounds and with diverse communities.

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