Principles of Cultural & Linguistic Competence (CLC) in Medical Research

For Presentation to The North Florida Chapter of The Society of Clinical Research Associates (SOCRA)
UF Health, Gainesville & Jacksonville • The Mayo Clinic Jacksonville & The University of Miami Miller School of Medicine

Heidi Saliba, BA
hsaliba@peds.ufl.edu
Assistant Director, Communications & Training
Pediatric Integrated Care System (Ped-I-Care)
Overview

Objective 1:
What is CLC, and what are our responsibilities under the ACA?

Objective 2:
How do we incorporate CLC practices into medical research?
What is Cultural Competence?

*Cultural competence is “a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals and enables that system, agency, or those professionals to work effectively in cross-cultural situations.”*

- Cross et al., 1989

• It is NOT:
  • Equal Opportunity, Affirmative Action, learning another language, or “sensitivity training,” although those may contribute to our levels of cultural competence
Definitions

- CLC = Cultural and Linguistic Competence
- Coined by Terry Cross, et al in 1989 monograph:

“...a developmental process that evolves over an extended period. Both individuals and organizations are at various levels of awareness, knowledge and skills along the cultural competence continuum.”
The continuum of cultural competence described by Cross, et al shows, “…at least six possibilities between two extremes…,” which include:

- Cultural destructiveness
- Cultural incapacity
- Cultural blindness
- Cultural pre-competence
- Cultural competence
- Cultural proficiency

Translation and interpretation are certainly part of CLC, but not the entirety – the landscape is much larger.
Primary Topics within CLC

Specific topics of interest within cultural and linguistic competence include, but are not limited to:

- Language and health literacy
- Age, class, and gender
- Race, ethnicity, and country of origin
- Sexual orientation
- Religion and spirituality
- Disability
- Education and perceptions of intelligence
- Technology and the Internet
- Workplace behaviors

Cross, et al describe 5 facets of the culturally competent system:

1. Values diversity
2. Has the capacity for cultural self-assessment
3. Is conscious of the dynamics inherent when cultures interact
4. Has institutionalized cultural knowledge
5. Has developed adaptations to diversity

They stress that each of these 5 elements must function at every level of the system in order for that system to be considered culturally competent.
Fundamental Concepts

• The term, “culturally competent communication” is relevant to the setting within which communication takes place.
  • Since we serve children with special health care needs, the focus of Ped-I-Care’s training is on communications with those who have disabilities.
• The weight of responsibility is on healthcare professionals, rather than patients, to set the stage for communicative understanding.
• Cultural and linguistic competence is not just nice addition to the human resources checklist, but rather the foundation of professionalism itself.
Fundamental Concepts

Ped-I-Care’s Model of Cultural Competence

Professionalism

What You Have
Skills, Knowledge, Education

How You Use It
Communication, Chosen Behaviors

Attitude

Cultural and Linguistic Competence

• Estimated direct & indirect costs (2003-2006) of racial & ethnic disparities in health care in US $229.6 billion

• Most common healthcare disparities for minorities:
  • **Access to care** - System structural and financial barriers prevent from receiving high-quality care
  • **Safe care** - Experience more medical errors with great clinical consequences
  • **Evidence-based** - Less evidence-based care; less likely to receive preventive health services.
  • **Timely** - More likely to wait for same procedure.
  • **Efficient** - Higher rates of ER utilization, hospital admissions as well as longer inpatient stays.

---

Under the Affordable Care Act (ACA):

1. Providers must act with cultural and linguistic competence
2. All groups, organizations, practices, and institutions receiving federal funds relating to health care must have a CLC plan. It must be annually planned, taught, measured, and reevaluated.
3. Definition, direction, guidance falls under purview of Secretary of Health & Human Services
How Does This Apply to Our Day-to-Day Duties in Medical Research?

• Solid, informed interactions with members and patients involve thorough, appropriate, and effective communication.
  • When translation services are necessary, use professional, certified interpreters rather than family members or friends except in emergency circumstances.
• Without some level of cultural competence, health care professionals risk misinforming, misunderstanding, misdiagnosing, and ultimately mistreating those whom they serve.
  • Patients are less forthcoming with professionals they don’t trust or can’t identify with, and less likely to follow their instructions.
Vulnerable Populations

• Some members or patients may not be able to advocate for themselves or their families as well as others, or may not feel comfortable doing so even when they feel they should.

  • Children
  • Immigrants or people whose native language is not English
  • People with special health care needs
  • People who are cognitively impaired
  • People who receive financial assistance with medical services
  • People who have diminished literacy or numeracy skills
  • People who feel like outsiders or are fearful for some reason
Vulnerable Populations

- People who are members of vulnerable populations may not feel comfortable questioning providers about alternative treatment options.
- They may or may not understand treatment directions.
  - They may fully understand treatment directions but choose to disregard them because of conflicts with their personal beliefs or culture.
- They may have trouble following prescription instructions, especially if written in medical language/coding.
  - They may fully understand prescription instructions but choose to take less than prescribed so that it lasts longer or possibly because they don’t like the medication’s side effects, or other reasons.
In the medical research setting, remember:

- 2-way trust is essential
  - You are working to earn study participants’ trust and respect just as they are working to earn yours

Study participants need to know:

1) You know what you’re doing
2) The entire research team knows what they’re doing
3) The research team is in communication with one another and the study population
4) Patient safety is your #1 concern
5) Nothing fishy/non-transparent is going on
6) Everything is well-coordinated, well-thought-out, and above par
7) How and when to contact you, and for what reasons
In the medical research setting, remember:

1. Your pool of research participants should be reflective of the persons for whom the drug, device, or intervention is intended
   - If studying sickle cell, participants should be mostly African-American
   - If studying a drug or device that may or will be used in children, be sure to include children at the appropriate stage of your research
     - Drugs for adults do not necessarily translate well for children, even when dosages are adjusted
   - Women and minorities have historically been excluded from scientific investigations
In the medical research setting, remember:

- The informed consent process is the most important time to build trust and respect
  - Learn to read potential participants’ body language
  - A ‘yes’ with closed body language and very little voiced interest is most likely an indication of participants’ perception that obligatory obedience is the way of all medicine
- Make it safe for all participants to say no, especially members of vulnerable populations
- Encourage interaction and questions
- Involve everyone in the room
- Express confidence in your study, the study team, and the institution
In the medical research setting, remember:

- The nature of informed consent = choice
- The nature of sticking to a protocol = following directions
  - Research professionals must balance communication of the voluntary nature of participation with the need to stick to directions exactly
Cultural Considerations

• Doctors, and by extension healthcare workers in general, are considered authorities and many people will do whatever is asked or suggested regardless of how they feel about it
  • Work to control implied influence
  • Give a neutral presentation
  • Discuss other treatment options, especially if they are standard and appropriate
  • Do not subtly or overtly penalize the other person for choosing not to participate
    • Shrugging shoulders, heavy sighing, “well, okay, but...,” or, “you’re missing out...,” etc.
# The Importance of Words: Coercive/Persuasive vs. Choice Words

<table>
<thead>
<tr>
<th>No</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>What you have to do</td>
<td>What we ask</td>
</tr>
<tr>
<td>You have to</td>
<td>If you choose to participate</td>
</tr>
<tr>
<td>You don’t have to participate, <em>but</em>...</td>
<td>You don’t have to do this.</td>
</tr>
<tr>
<td>We need 30 study subjects</td>
<td>Your decision won’t affect your care in any way.</td>
</tr>
<tr>
<td>We need you to...</td>
<td><em>Would you</em> be interested in?</td>
</tr>
<tr>
<td>We’re trying to get this drug approved</td>
<td>We’re testing a new medication</td>
</tr>
<tr>
<td>You would be perfect</td>
<td>You can participate <em>if</em> you like</td>
</tr>
<tr>
<td>I would love to have you participate in...</td>
<td>There’s a new study <em>you might be</em> interested in...</td>
</tr>
<tr>
<td>I’m excited to tell you about this new study...</td>
<td>There is another option <em>you may be</em> interested in.</td>
</tr>
<tr>
<td>You could make some money</td>
<td>We do offer a gift card if you choose to complete the study</td>
</tr>
<tr>
<td>If you sign up, you’ll have to...</td>
<td><em>If you choose to participate, what we would ask is</em>...</td>
</tr>
</tbody>
</table>
### The Importance of Words: Litigious vs. Approachable Words

<table>
<thead>
<tr>
<th>No</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>We're investigating the relationships....</td>
<td>What we're looking at is...</td>
</tr>
<tr>
<td>This investigation...</td>
<td>This study...</td>
</tr>
<tr>
<td>The principal investigator</td>
<td>The study leader</td>
</tr>
<tr>
<td>parent-child dyads</td>
<td>parent-child teams</td>
</tr>
<tr>
<td>physician</td>
<td>doctor</td>
</tr>
<tr>
<td>There is no penalty for not participating.</td>
<td>Your choice to participate, or not, will not affect your care/employment in any way.</td>
</tr>
<tr>
<td>compensation package</td>
<td>gift cards, payments</td>
</tr>
<tr>
<td>the TOEFL</td>
<td>the first survey</td>
</tr>
</tbody>
</table>
The Importance of Words: Truth and Tone

<table>
<thead>
<tr>
<th>No</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>There are no risks</td>
<td>There are no <strong>known</strong> risks beyond that which is considered normal for any study...</td>
</tr>
<tr>
<td>There are no benefits</td>
<td>There are no <strong>direct</strong> benefits</td>
</tr>
<tr>
<td>your level of understanding</td>
<td>how you make decisions</td>
</tr>
<tr>
<td>your abilities to comprehend</td>
<td>how you decide</td>
</tr>
<tr>
<td>Is that clear?</td>
<td>Does that make sense?</td>
</tr>
<tr>
<td>how your child perceives her quality of life</td>
<td>what Sarah thinks about how asthma affects her</td>
</tr>
<tr>
<td>how your decisions affect his healthcare</td>
<td>how you make decisions and how Sam feels about dealing with asthma</td>
</tr>
</tbody>
</table>
The Importance of Words

No: “What you have to do…”
No: “You can’t do that.”
Yes: “What we ask is…”

No: “No, that’s not right…”
Yes: “Actually, what we do is…”
Yes: “You’re right; x, y, and z are that way, but for this one it’s a little bit different. Let me show you what I mean...over here,...”

No: “You can’t get the gift card unless you finish the survey.”
No: “I’ll have to take the gift cards away unless...”
No: “If Johnny doesn’t finish, neither one of you gets the gift card.”
Yes: “What we ask if for both of you to complete all of the portions of the surveys, so that we can give the gift cards to each of you. It’s no problem if you need more time/want to come back to start this on another day.”
Respectful, effective communication is at the heart of cultural competency. It comes from a place of professionalism, which is driven by a good attitude, and it involves:

• Active listening with appropriate responses
• Being sensitive to the other person’s background, needs, and abilities
• Paying attention to both surface and subtle communication cues
• Words, body language, setting
• Sending clear, concise, and consistent messages
Components of Respectful, Effective Communication

- Demonstrate appreciation/value for patient’s choices, behaviors, special qualities
  - “You have obviously worked hard on this...”
  - “That was tough; you handled it well.”
  - “You have obviously researched this problem...”
  - “Let’s see if I can add to your knowledge...”
- Shared decision making
- Empowering the patient/family
- Listening to their concerns: non-judgmental
- Separate yourself from the culture of dismissiveness!
  - Don’t “blow off concerns”
- DO be respectful of everyone’s time
ICF must be written at the eighth grade or lower level to meet UF’s IRB requirements.

- Medicaid requires fourth grade or lower level.

- Innumeracy is more common than we realize.

- Perfect English ≠ perfect understanding.

- English + accent ≠ illiteracy or ignorance.

- Not a speaker of English ≠ lack of education.

- People remember about 10% of what they hear.

- Do not assume race or gender.

- Questions of sexual activity may deeply offend, especially if the patient is unmarried.
  - Explain why you are asking/discuss standards of care.
If someone is deaf, they will be unable to hear you no matter how loud you speak.
If someone speaks another language that you do not speak, they will not be able to understand you no matter how loud you speak.
If someone has a learning disability, that does not mean he/she also has far-reaching intellectual disabilities.
If someone uses a wheelchair, that does not mean they are incapable of doing anything on their own.
If someone receives Medicaid assistance, food vouchers, or public assistance, that does not equate to or call for a commentary on their character.
Be very careful using the term, “those people…”
Cultural Considerations

- Not everyone believes it is respectful to look you in the eye.
- In some cultures, it is best to have care provided by a member of the same sex as the patient.
- In some cultures, women will allow their husbands to make decisions for them.
- In some cultures, it is considered rude to show the bottom of your shoe.
- Some religions forbid blood transfusions.
- Some religions forbid the photographing of individuals.
- Sexual preference and practice may not be revealed, or revealed in full, thus affecting the risk-benefit ratio and the course of care.

Photo credit: Amanda Mills/CDC
All programs, providers, and practitioners need to know:

• Almost all (95%) adolescents have access to the Internet, and of those, more than half (51%) use it to search for health information.\(^2\)\(^2\)
• They are searching for information on illnesses or diseases they or a family member have been diagnosed with (39%) as well as information on food and nutrition (39%).
• More than one-third (34%) have changed the way they care for themselves based on information they found on the Internet, but only 7% have ever initiated discussions with their doctor about what they’ve found. Many (41%) would be interested in guidance about using the Internet to get health information.
• 10% believe, “you can trust all the health information that is found on the Internet.”
• Most adolescents use social media and user-created/open-forum sites (Facebook™, YouTube™, Twitter™, and Wikipedia™) as their main sources of Internet information.

“Coaching” Websites

From the *Medical Fraudomatics* presentation:

• Clinicians’ vulnerabilities:
  • Lack of knowledge regarding coaching websites and level of sophistication with these new tactics
  • Lack of access to prior records – makes it difficult to know consumer is scamming
  • Lack of communication in medical records and among practitioners within the same office
  • Pain is difficult to quantify; no one wants to see others suffer
    • Abusers (and authors of coaching websites) are aware of this and use it to their advantage

---

what to say to your doctor to get xanax
what to say to your doctor to get viagra
what to say to your doctor to get adipex
what to say to your doctor to get adderall
what to say to your doctor to get vicodin
what to say to your doctor when depressed
what to say to your doctor about anxiety
what to say to your doctor to get phentermine
what to say to your doctor to get promethazine codeine
what to say to your doctor to get prescribed adderall
DO:

- Acknowledge and address the participants’ questions, challenges, and concerns, even if you disagree with them
  - These are clues to what is going on below the visible surface
  - This is where trust is built
  - People don’t necessarily need to agree with you, or you with them. They need to be listened to and responded to with courtesy and respect.
CLC in the Medical Research Process

DO:

- Use choice words rather than control words
  - “What we ASK” rather than, “What you HAVE to do...”
- Use simple terms rather than research jargon
  - “The study team” rather than, “The principal investigator and investigational associates...”
- Use empowering words rather than emotional ones
  - “You might find that you prefer....” rather than, “You’ll probably run into this problem....”
DO:

- Use people-first language, including and especially behind closed doors
  - “People who have HIV” rather than, “AIDS patients”
  - Who you are in private is who you really are. Eventually it will become public. Privately practice what you publicly preach.
DON’T:

• Trick people or lie to them.
• Try to make a “fast sale” in the informed consent process
  • “You’ll probably want to just throw this (Informed Consent Document) away (rather than reading it)...”
• Conduct informed consent at the wrong time
  • When someone is under the influence of pain medication
  • When someone is desperate and scared
  • When a member of a vulnerable population has no one there with them to help them make an informed choice
DON’T:

- Condescend or patronize
- Make fun of others
- Express dissatisfaction with having to go through a rigorous informed consent or research process
- Set people up for expecting a miracle
- Sell your study on the basis of no other option
- Treat anyone, including your staff, with disrespect
- Be dismissive
- Bully
- Be surprised when you’re audited, if you’ve engaged in any one of the “Don’t” items
DON’T:

- Settle for “fluff” training in communications and informed consent
- Assume that just because a training session is related to communications and human interactions, that it is automatically “fluff”
- Solid, specific, well-informed communications training is the secret sauce that separates fast-food research from gourmet investigations, regardless of the nature or intensity of the study
How Does This Apply to Our Day-to-Day Duties in Medical Research?

- Truly CLC conversations, practices result in:
  - Better service to patients and study participants
    - Increased patient satisfaction
  - Highly-competent, well-informed staff
    - Staff retention likely to increase
    - Staff relationships, internal communications likely to benefit
  - Stress reduction, knowing you and study participants have open, clear, constructive, and ongoing interactions
  - Increased confidence in research findings, in that your results are framed by contextually appropriate understandings
1. If you don’t/your organization doesn’t have a CLC plan, you need one yesterday.

2. Researchers and clinicians who practice patient-centered and family-centered communications and care are likely already providing CLC care.

3. Clarity, appropriateness, and timing of communications is the difference maker in all phases of clinical activities and the research process. Invest in it accordingly.
Contact:

Heidi Saliba
hsaliba@peds.ufl.edu
(352) 627-9196
References


27. Quotation from a deaf man, ‘Cultural Patterns of Deaf People’ by Linda A. Siple.


