EMPACT

Effective Methods of Communication Between Researcher and Participants

A presentation by the EMPACT consortium

EMPACT
11/1/2012

Contents

Why is culturally competent communication important in clinical trials recruitment?

Clear and effective communication is the first step in establishing a trusting relationship between you and study participants, a key element in the recruitment of minorities to clinical trials.

Successful communication can lead to full transparency of research protocol for both you and your participant.

However, Cultural Barriers May Hamper Traditional Communication Methods

Researchers and Participants may become confused by:

- cognitive constraints
- behavior constraints
- and emotional constraints

Cognitive constraints are background information into which all new information is compared to or inserted into.

Behavior Constraints are differences in the meaning of verbal and nonverbal communication.

And *Emotional Constraints* are the differences in acceptability of emotional displays

To further explain: Cognitive constraints

…are the ways people view the world based on their past experiences and can be based on a myriad of factors, including:

- Religion
- The area in which you live
- Literacy rate
- Socio-economic status
- and educational attainment

Cognitive constraints can affect a participant's healthcare decisions and how a participant may respond to clinical trials. This is based on historical accounts of unethical research designs.

History of Uninformed Consent

In the 1840's, J. Marion Sims performed Gynecological experiments on African American slaves

From 1932-1972, the Tuskegee Syphilis Experiment withheld treatment for syphilis from African Americans known to be infected. .

From 1933-1945, Special Japanese military units conducted experiments on civilians and POWs in China.

And more recently, from 1989-2008 Havasupai Indians' blood samples were used for genetic research on schizophrenia.

Ultimately, there must be a balance between ethics and medical research.

Behavior constraints

…are the differences in culturally acceptable behavior, affecting both how a participant behaves and how he/she perceives others behaviors.

For example, *Eye Contact:*

- In the Asian Culture direct eye contact, especially between two people of a different age range, is considered rude. It is polite to look down when speaking with those of higher social ranking such as an elder.
- In Western Culture direct eye contact is a sign of honesty and attentiveness, a lack of eye contact indicates dishonesty or a lack of interest.

Emotional constraints

…are differences in cultural level of acceptability toward displays of emotion, especially in social situations. Therefore, although the same emotion can be felt across cultures, the method of displaying these emotions can vary widely.

For Example, *Grief:*

- Emotional displays showcasing grief varies widely amongst cultures. Public display of negative emotions, such as grief, is generally not acceptable in Asian cultures.
- In Middle Eastern and African-American culture, public display of grief is permitted, and even encouraged.

Communication Models

There are multiple communication models available to help facilitate culturally competent communication between researcher and participant. We're going to look at three of them - LEARN, ETHNIC, and RESPECT.

The LEARN Model stands for

- Listen
- Explain
- Acknowledge
- Recommend
- and Negotiate

Through this case study of Alicia Mercado's Story, we will apply concepts from the LEARN model

Alicia Mercado is a 60-year-old woman from Puerto Rico. As she gets older, her day-to-day life revolves more and more around her chronic illness – most predominately diabetes, hypertension, and asthma. Her mother passed away from cancer and Alicia fears she will face the same fate. She has missed many appointments and can be classified as a non-compliant/disjointed patient.

Dr. Afua Forson is Ms. Mercado's physician. Today, Ms. Mercado will be coming in for an appointment.

LEARN's first concept: Listen

Listen with empathy to fully understand your participant's point of view, concerns, and confusions. *Ask* open ended questions that will illicit an explanatory answer from your participant. Also *Identify* potential barriers and be sure to address them.

Actively listen in order to differentiate between your point of view and the participant's point of view.

When the concept 'LISTEN' is applied to the Case Study:

Dr. Forson's asked multiple open-ended questions to Ms. Mercado in order to develop a comprehensive view of the situation:

"Can you tell me why you haven't been able to make your appointments or why it has been difficult for you to come into the office?"

"Would you be comfortable talking about the problems or the distractions that have been going on since we last saw each other?"

Through this, it is identified that Ms. Mercado is suffering from social stressors that make it hard for her to be compliant with the required medical treatment.

LEARN's next concept: Explain

Simplify complicated medical terms – determine and meet your participant health literacy needs. For help, you can find a reading assessment tool at the listed website.

Address participant's concerns and offer an explanation that does not impede on cultural beliefs. Continuing on with Alicia's story…

When the concept 'EXPLAIN' is applied to the Case Study

For Ms. Mercado, someone with no medical background, complicated medical terms can be confusing, especially since English is not her native language. Dr. Forson explained and showed Ms. Mercado what a peripheral neuropathy pen is, addressing Ms. Mercado's fear of needles.

LEARN's third concept : Acknowledge

Acknowledge the differences between your participant's point of view and your own point of view.

Do not dismiss concerns based on your own beliefs.

When the concept 'ACKNOWLEDGE' is applied to the Case Study

Ms. Mercado believes in a combination of prescription drugs and homeopathic remedies, such as taking hypertension drugs as well as garlic to control her blood pressure.

Dr. Forson acknowledged everything that Ms. Mercado was taking, including the use of homeopathic medicine. This is important in establishing a sense of trust.

A combination of homeopathic care (from cultural and/or religious beliefs) and prescription drug is common among patients. Many times, as long as the homeopathic remedies do not interfere with the prescription drug, it is not harmful for patients to use both.

LEARN's 4th concept: Recommend

Recommend solutions that respect and work in conjunction with the participant's cultural beliefs and still adhere to study protocols.

LEARN's 5th concept: Negotiate

Negotiate a plan to move forward that incorporates the participant's inputs, concerns, and agreement to adhere to study protocols. Remember that incorporation of traditional cultural treatment may not interfere with participation in clinical trials.

When the concepts 'Recommend' and 'Negotiate' are applied to the Case Study:

Dr. Forson and Ms. Mercado compromise on a treatment plan. Dr. Forson focused on the most crucial of Ms. Mercado's chronic health conditions, diabetes. Dr. Forson provided Ms. Mercado with a book to track her blood sugar level and, in exchange, Ms. Mercado agrees to return for a follow up appointment in two weeks.

The plan of treatment is feasible for Ms. Mercado to comply with and still functional in helping her control her diabetes.

When applied successfully the L.E.A.R.N. model can result in:

Cultural Competent communication between researcher and participant

Cognitive Restructuring of a participant's view towards clinical trial

…And establishment of *a trusting relationship.*

Try to Remember

The steps of the L.E.A.R.N. model are not always in sequential order and need not be applied that way. In each interaction with the participant, one or more steps of the model can be applied. Body language is as much a part communication as verbal language so be sure your body language is congruent with your spoken words.

You can learn more from the following resources.

- Gilbert, MJ. A Manager's Guide to Cultural Competence Education for Health care Professionals. The California Endowment, A Partner for Healthier Communities. http://www.calendow.org/uploadedfiles/managers_guide_cultural_competence(1).pdf
- Berlin, E. & Fowkes, W.A.(1983). A teaching framework for cross-cultural health care. Western Journal of Medicine, 139:934–938. Available from http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=1011028&blobtype=pdf
- Welch, M. (1998). Enhancing awareness and improving cultural competence in health care. A partnership guide for teaching diversity and cross-cultural concepts in heath professional training. San Francisco: University of California at San Francisco.

- Ting-Toomey, Stella. Felipe, Korzenny. (1991) Cross-cultural Interpersonal communication. International and intercultural communication annual, Vol. 15. Thousand Oaks, CA, US: Sage Publications, Inc. viii283.
- Cultural Barriers of Effective Communication. http://www.colorado.edu/conflict/peace/problem/cultrbar.htm

This presentation has been brought to you by EMPACT, enhancing minority participation in clinical trials.