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How Cultural Factors Affect Minority Recruitment to Clinical Trials

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What is Culture?

According to the Office of Minority Health, culture refers to the integrated patterns of human behavior that include language, thoughts, communications, actions, customs, beliefs, values and institutions of racial, ethnic, religious or social groups.

Culture Affects

Language, Social and Health Behaviors, Self-care, Celebrations, Lifestyle Attitudes, Communication Styles, Death, Art and Music, Social Expectations, Clothing...It affects *everything*.

One might imagine culture as an iceberg.

When we see an iceberg the only portion that is visible is what is above water. Similarly when individuals think of culture they only think about what they can "see" (i.e clothing, music, food, behaviors etc). Below the surface, culture is ingrained in the beliefs, attitudes and values individuals bring with them everywhere they go.

But there is more below the water - attitudes, core values, and institutions of influence.

Attitudes are how the core values are reflected in specific situations in daily life such as working and socializing.

Core Values are learned ideas of what is considered good or bad, desirable or undesirable, acceptable or unacceptable.

Institutions of Influence are the forces which create, define, and mold a culture's core values. Some examples of such forces are economics, religion, the media, history, family, and educational systems.

What is Cultural Competency? A Moving Target.

Cultural and linguistic competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross- cultural situations. 'Culture' refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups

'Competence' implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities.

The elements of culture influence beliefs and belief systems surrounding health, healing, wellness, illness, disease, and delivery of health services

Why is Cultural Competency Important to Clinical Trials Recruitment?

For two reasons: recruitment and retention.

Cultural competency provides researchers with the tools necessary to communicate and deliver services that are respectful of and responsive to the health beliefs, practices and cultural and linguistic needs of diverse patients, bridging the gap between participant concerns and that of the researcher.

Once a participant is in a clinical trial, it is crucial for the researcher to maintain trust and respect by continually providing culturally competent care.

Enrollment by Race and Ethnicity

A study by the National Cancer Institute shows the clinical trials enrollment rates, broken down by race and ethnicity. By race, the majority were white, 8% were Black / African Americans, 2.8% Asian / Pacific Islander, 0.5% were Native American/Alaskan Native and a small remainder were Mixed race.

By ethnicity, 5.6% who enrolled were Hispanic / Latino, while the rest were non-Hispanic /Latino.

Source: "Baseline Study of Patient Accrual Onto Publicly Sponsored Trials," Coalition of Cancer Cooperative Groups for the Global Access Project, National Patient Advocate Foundation, April 2006.

Perceptions of Disparities in Health Care

According to the National Survey of Physicians published in March 2002 by Kaiser Family Foundation, the perceptions of health care disparities between doctors and the public differ significantly.

When asked **"**Generally speaking, how often do you think our health care system treats people unfairly based on whether or not they have insurance", 72% of doctors responded with very or somewhat often while 70% of the public responded with very or somewhat often.

When asked "generally speaking, how often do you think our health care system treats people unfairly based on how well they speak English", 43% of doctors responded with very or somewhat often while 58% of the public responded with very or somewhat often.

When the survey asked "how often do you think our health care system treats people unfairly based on what their race or ethnic background is", 29% of doctors responded with very or somewhat often while 47% of the public responded with very or somewhat often.

And lastly, when asked **"**how often do you think our health care system treats people unfairly based on their gender", 15% doctors responded with very or somewhat often while 27% of the public responded with very or somewhat often.

Source: Kaiser Family Foundation, National Survey of Physicians, March 2002 (conducted March-October 2001); Survey of Race, Ethnicity and Medical Care: Public Perceptions and Experiences, October 1999 (Conducted July – Sept., 1999)

Let's view a case study.

Justine Chitsena is a young Khmu-American girl who has an atrial septic defect, a hole in the wall of her heart. Her cardiologist recommends open chest surgery to seal up the hole but her grandmother is very opposed to the idea.

In the case study we observed different views on health.

To the Chitsena Family, Justine appears healthy, not sick. They believe a surgical scar, or any scar inflicted on a body stays with you even into your next lives. And it is better to have a shorter life then to be scarred forever.

To U.S. Medical Professionals, Justine has a hole in the muscle wall of her heart and she needs open chest surgery in order to seal the hole in her heart. Surgery can extend Justine's life and prevent her from having heart complications later on.

Things to consider for this case: cultural background and family dynamics.

How would you approach a participant whose cultural background and family dynamics is different from yours? How will you ensure that you are being respectful of their cultural beliefs? How can you ensure your own cultural biases will not affect your interactions with study participants?

For other scenarios, using the five elements of the culturally competent care system can be a good start:

Valuing Diversity means we must recognize and respect that diversity is important. Accept differences in communication, one's view on life, health, and family.

Cultural Self-Assessment is the realization that aside from being a trained researcher who interacts with diverse groups of people, you are also someone who comes from a unique cultural background.

Know that there are *Dynamics of Differences* and two or more cultures may clash with each other. Be aware and pay attention to the dynamics that surround cultural interactions.

And *Institutionalize cultural knowledge*, by incorporating newly attained knowledge into ongoing development of practice skills.

Finally, *adaptation to diversity* demonstrates the approaches and actions necessary to incorporate cultural competency into the health system.

Sources:

1. Cross TL, Bazron B, Dennis KW, Isaacs MR (1989) Towards a Culturally Competent System of Care. Vol. 1. Georgetown University Child Development Center, Washington, DC.
2. Thorton, S. Addressing Cultural Competency in Research: Integrating a Community-Based Participatory Research Approach. ALCOHOLISM: CLINICAL AND EXPERIMENTAL RESEARCH. Vol. 27, No. 8 August 2003

The cultural competency spectrum illustrates the different levels of cultural competency a person can attain.

At the lowest level is cultural destructiveness where cultural differences are seen as a problem and the person identifies one culture as being superior to others.

The next level up is Cultural incapacity where one lacks awareness and skills; perpetuates stereotypes and is paternalistic toward non- dominant groups.

Cultural Blindness describes a person who assumes all cultures are alike and believes culture does not account for differences.

A person is culturally pre-competent when he/she recognizes differences but is complacent in making changes.

With basic competency, an individual accepts, appreciates & values differences and seeks opinions of diverse groups.

To achieve advanced competency, one must actively educate those less informed and seek to interact with diverse groups.

Case Study: continuing Justine's story

During one of Justine's visits to the cardiologist, the cardiologist explained to Justine's mother why she believes it is important for Justine to get the surgery.

Things to consider:

How did the cardiologist respond to the family's cultural beliefs? How did Justine's mother respond to the cardiologist? Is this a good example of cultural competency? Why or why not?

Lessons learned:

Recognize, respect, and accept that the participant's family dynamics and cultural beliefs can be very different from your own. Apply this to future clinical trials recruitment efforts.

Pay attention to non-verbal cues such as participant mannerisms. It is important to not only listen to what is being said, but also to hear what isn't being said. Pay attention to how a participant behaves.

If put into a similar situation, how would you approach, react, and communicate with the study participants?

If you want to learn more about each ethnicity, listed are links to additional resources that can help you

- African American http://iccnetwork.org/cancerfacts/ICC-CFS1.pdf
- American Indian/Alaskan Natives http://iccnetwork.org/cancerfacts/ICC-CFS2.pdf
- Asian American http://iccnetwork.org/cancerfacts/ICC-CFS3.pdf
- Hispanic/Latino Americans http://iccnetwork.org/cancerfacts/ICC-CFS4.pdf

You can learn more about cultural competency from the following resources

1. Much of the information widely used concerning cultural competency derives from ground-breaking series of monographs on development of a culturally competent system of care called, Towards a culturally competent system of care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed (Terry L. Cross et al., 1989). More information is available at http://www11.georgetown.edu/research/gucchd/nccc/.

2. The NIH Office of Minority Health pages on "Cultural Competency" are available online at http://www.omhrc.gov/templates/browse.aspx?lvl=1&lvlID=3 and include nationwide standards, policies, training tools, information about relevant laws, and other resources.
3. Georgetown University Center for Cultural Competence, http://www11.georgetown.edu/research/gucchd/nccc/
4. Georgetown University Center for Cultural Competence, Self-Assessment Checklist for Personnel Providing Behavioral Health Services and Supports to Children, Youth and their Families, http://www11.georgetown.edu/research/gucchd/nccc/documents/ChecklistBehavioralHealth.pdf (PDF - 84 KB)
5. "Improving Cultural Competency: Overview and Introduction," National Diabetes Education Program, http://betterdiabetescare.nih.gov/ISSUESculturalcompetency.htm
6. "Cultural Competency," National Women's Health Information Center, http://www.womenshealth.gov/healthpro/cultural/
7. "Cultural and Linguistic Competency," Agency for Healthcare Research and Quality, http://www.ahrq.gov/path/compath.htm
8. "Cultural Competency," Multi-Cultural Resources for Health Information available from the National Library of Medicine, http://sis.nlm.nih.gov/outreach/multicultural.html#a0
9. "Culture, Diversity & Health Disparities in Medicine," Bioethics Resources on the Web, http://bioethics.od.nih.gov/culturalcomp.html

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