

**reConsidering Culture in Research:
Attracting and Retaining Culturally Diverse Research Participants**

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Abstract

The U.S. Census projects that by 2060, minorities will comprise 60 percent of the population, presenting challenges to researchers using human subjects with widening cultural, gender, identity, and disability characteristics.

Keywords: diversity in research, globalized research, inclusive research, intersectionality in research participants, research participant diversity

Today, minorities collectively make up about 37 percent of the U.S. population; however, research suggests minorities will comprise nearly 60 percent of the population by 2060 (Frey, 2018). Moreover, as our population grows more diverse, so will the reach of intersectionality across races. According to the 2020 census data, the fastest-growing racial or ethnic group in the United States is people who are two or more races. This population is projected to grow nearly 200 percent by 2060. The only group projected to shrink is the non-Hispanic White population, which is expected to contract nearly 19 million people (Vespa et al., 2020). The expected growth in the United States in the next 40 years presents a unique challenge to researchers as cultural, religious, gender, identity, and disability characteristics widen among human research subjects. This paper focuses on the challenges of considering culture in research and suggests it is time to consider making amendments to the documents governing human research subjects, to include more inclusive language and measurable actions. In search of a solution, this researcher turns to their community of practice asking for collaboration to address this need.

This paper asserts that despite our growth and changing multicultural population, a unicultural perspective persists in academic research. This perspective damages research outcomes by limiting alternative perspectives, in some cases locking them out entirely (Papadopoulos, 2003). This perspective partly exists because the language is vague, and the requirements for cultural inclusivity do not exist within the body of the guidelines governing research with human participants. Specifically, there are challenges concerning how research participants are protected. This paper will discuss the current guidelines governing research with human participants presenting an argument for updating the guidelines to reflect more inclusive language to keep pace with our changing demographics. Furthermore, this paper posits that adult educators and practitioners are most well-suited for taking on this endeavor. Adult education has a long history of advocating for social justice and social change through rich critical research, advocacy, and practice. Finally, this paper will conclude with a call to action – starting with the Institutional Review Board (IRB) at our home institutions, universities, and organizations, we must set immediate goals for addressing researchers' understanding of culture in the context of their human research subjects. Starting with the treatment of culture, designing a comprehensive trauma-informed approach to cultural sensitivity training or assessments supporting integrity in future research with human subjects while working collaboratively, identifying the necessary changes needed to make to the Belmont Report and The Common Rule inclusive and reflective governing documents.

Background

The introduction of IRBs in the United States was spurred by reports of research involving human subjects gone wrong. Following World War II, the Nuremberg trials exposed the use of unethical research designs and methods. This discovery produced the Nuremberg Code in 1947, followed by the Declaration of Helsinki in 1964. Both documents were intended to serve as clear statements on ethical research standards of human subjects (Beauchamp, 2020). However, their impact in the United States was ambiguous and not legally binding because they were produced by a nongovernmental organization and not by an authoritative legal body. Suspicious and scrupulous human subject research was still underway in the United States, including the Willowbrook study of hepatitis transmission on mentally impaired patients, the Tuskegee Syphilis Study, and Jewish Chronic Disease Hospital, which were all conducted and discovered long after the Nuremberg Code was created (Moon, 2009; Spellecy & Busse, 2021).

In response, the National Research Act of 1974 was passed, creating the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (Beauchamp, 2020; Spellecy & Busse, 2021). The commission was charged with "identifying the basic ethical principles that should underlie the conduct of biomedical and behavioral research involving human subjects and developing guidelines to assure that research is conducted in accordance with those principles" (OHRP, n.d.). As a result of the commission's work, they published the Belmont Report in 1979. Compared to the Nuremberg Code, the Belmont Report was much broader and established three basic ethical principles: 1. Respect for persons, 2. Beneficence, and 3. Justice. It also established the network of IRBs and codified informed consent as part of the research protocol. The recommendations of the Belmont Report became federal law organized by the Office of Human Research Protections (OHRP), operating under the Department of Health and Human Services (DHHS), and local IRBs administer all guidelines at all institutions operating with federal funding (Beauchamp, 2020; OHRP, n.d.).

The Belmont Report remains the guidepost for all ethical research using human subjects today in the United States. It has been amended twice since its creation, most notably the OHRP met in 1991 to extend protections for various vulnerable populations, known as the Common Rule, adopting various subparts which include:

Subpart B, "Additional Protections Pertaining to Research, Development, and Related Activities Involving Fetuses, Pregnant Women and Human in Vitro Fertilization," became final on August 8, 1975, and was revised effective January 11, 1978, and November 3, 1978.

Subpart C, "Additional Protections Pertaining to Biomedical and Behavioral Research Involving Prisoners as Subjects" became final on November 16, 1978.

Subpart D, "Additional Protections for Children Involved as Subjects in Research" became final on March 8, 1983 and was revised for a technical amendment on June 18, 1991 (OHRP, n.d.).

While the current guidelines provide a foundation for ethical research for protecting human subjects in research, it does not include culturally inclusive and appropriate language. The criteria are vague, providing a unique opportunity to develop protocols to meet the demands of our future demographics.

Supporting Literature

Like the health sciences, some disciplines have done a better job than others at crafting language and guidelines for cultural sensitivity in research. Beauchamp (2020) explains that the health professions have long been at the forefront of teaching and emphasizing the importance of culture in the context of patient center care among clinicians; however, while cultural competency education for clinicians is becoming widespread, cultural competency education for [clinical] researchers has not progressed at the same pace. The literature suggests a lack of cultural competence of researchers may hinder their ability to engage specific communities, such as with minority or non-English speaking individuals, and may lead researchers to impose their beliefs, values unknowingly, and patterns of behavior upon those from other cultural backgrounds (Beauchamp, 2020; CRHD, n.d.; Leininger, 1995; O'Brien et al., 2006).

Although research in the health sciences (i.e., biomedical, clinical, health services, and community-based participatory research) has only recently begun to explore the importance and linkages between culture and research design, analysis, and interpretation (Bryd et al., 2021; Harvard Clinical and Translation Science Collaboration, 2009), they have discovered there are substantial participant barriers to research among minority populations, which have negatively impacted enrollment and retention rates of minorities in research studies (Bryd et al., 2021). In addition, there are researcher, structural and organizational barriers that can contribute to low recruitment and retention of minority groups (Betancourt, et al., 2005; Robinson & Trochim, 2007). The appropriate culturally sensitive language and considerations must be integrated into the research process to address these barriers and engage, recruit, and retain specific demographic populations. Starting with the planning stages of the research study, researchers must ask whether they are using the appropriate constructs, measures, and methodology concerning their target population, which requires a dual commitment to respecting and honoring cultural values, beliefs, and needs, without sacrificing scientific rigor (Bryd et al., 2021; CRHD, n.d.).

A highly contended aspect of cultural sensitivity training centers around inclusive terminology (race, ethnicity, culture, gender, etc.) Many variables and understandings exist in the literature. Moreover, researchers tend to use the terms interchangeably, complicating measurement, heterogeneity, and risking essentialist research design (Papadopoulos, 2003). There are many terms and phrases across the literature used to describe and measure the degrees to which a person is aware of cultures beyond their own, such as *cultural competency*, *cultural humility*, *cultural awareness*, and *cultural pluralism* (Hall, 1976; Weaver, 2000; Zaldivar, 2019.). Further complicating matters is the extent to which culture has been taught to researchers and whether it was taught as a matter of competency. For example, Zaldivar (2018) explains that early in cultural competency education, if a person were visiting another country, they would learn about the culture, the common norms, and expected conduct. However, there has been a shift in thinking about this approach. Hall (1976) laid the foundation for a new wave of intercultural communication by introducing the concept of *cultural context*, which is a collection of unwritten rules that are hard to teach to others within the appropriate context. He further explains that the extent to which and how people understand other cultures is a continuum that spans from low to high and was not a finite lesson to be learned but instead experienced and embodied. Later, Weaver (2000) argued that cultural competence "is about helping individuals recognize that other cultures perceive time, relations, and hierarchy differently than we do and that each culture has its own cultural context" (Zaldivar, 2018, p. 2).

However, each of these phrases has complications; for example, the word *competency* indicates an end to the learning or a final destination – once a person is considered culturally competent, they never have to revisit the topic. While Hall (1998), Weaver (2000), and Zaldivar (2018) disagree with this assumption. Tervalon and Murray-Garcia (1998) advance cultural humility as "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" (p. 118). And Yeager and Bauer-Wu (2013) explain cultural humility as a lifelong process involving self-reflection and self-critique. During the reflection, the individual learns about another's culture by examining their own beliefs and cultural identities. Foronda et al. (2015) explain that cultural humility is a process of openness, self-awareness, egoless, and self-reflection and critique after engaging with diverse individuals in a world where power imbalances exist everywhere. In this discussion, Hall (1976) presents a metaphor stating culture is like an iceberg, proposing that culture has two components made up of the parts you can see and the other that you cannot. About 10% of culture is external and displayed on the surface, and the other 90% is hidden below the surface (deep culture) or internally. Hall often used the imagery of an iceberg to illustrate the metaphor further.

In addition to addressing cultural terminology in research, educating adult learners is central to this idea - creating more critically competent researchers provides a unique opportunity for the adult education community to create and deliver the appropriate tools and methods needed. Therefore, I assert that adult educators are ideally suited to provide the critical lens through which to explore cultural competency in research (Rowland, 2006) and create the tools needed to deliver and facilitate cultural understanding among researchers. Lastly, this study suggests that the adult education community should develop an assessment to measure the outcomes for further research implications and application to address the remaining domains of ethnicity, gender, religion, and disability. What constitutes cultural competence, awareness, or humility and how we define it may contribute to the lack of full representation in future research. It can be confusing for the researchers and the IRB committees if there are not appropriate and agreed-upon terms, definitions, and expectations.

Implications for Adult Education and Learning

Through action research, the adult education and learning community can make a significant statement about our specific skill set, demonstrate our expertise and make a lasting impact on the future of academic research. Part of action research is conducting research that seeks action to improve practice and study the effects of the action that was (or will be) taken. It also involves making decisions focusing on improving educational practice limiting generalizability. Most importantly, action research creates solutions and implements them as part of the research process (Creswell & Creswell, 2019; McMillan & Wergin, 1998; Riel, 2020).

Further, adult educators are ideally suited to provide the critical lens through which to explore cultural competency in research and create the tools needed to deliver or facilitate cultural understanding among researchers. "Adult educators have consistently examined and explored the intersection of issues of race, class, gender, socioeconomic status, sexual orientation, social justice, and oppression (Rowland, 2006, p. 331). We can take steps to prepare better all researchers who research in a globalized learning context. The results of this project could result in changes to IRB protocol impacting us locally. Additionally, the outcome of this study could have federal policy impacts resulting in the amendment of the Belmont Report,

expanding the Common Rule to be more inclusive further protecting human subjects and the integrity of academic research.

Conclusion

While the current IRB standards, the Belmont Report, and the Common Rule criterion provide a foundation for ethical research, the language of the criteria is vague, providing a unique opportunity to develop protocols to meet the demands of our future demographics. Further, I believe adult educators are ideally suited to provide the critical lens through which to explore cultural competency in research and create the tools needed to deliver or facilitate cultural understanding among researchers. “Adult educators have consistently examined and explored the intersection of issues of race, class, gender, socioeconomic status, sexual orientation, social justice, and oppression (Rowland, 2006, p. 331).

I am calling on my community of practice to identify a collaborative solution to this impending problem. Ideally, a group of 20-25 adult educators, content experts, and practitioners will consider the next steps. Some things to consider are terminology, choosing the words or phrases that best describe the act of researchers learning about culture. Other possible steps could include designing tools or assessments, defining the expected outcomes, and how to measure them. The outcome of this study could have far reached impacts; first, the recommendation is to start locally at our home institutions. We should be prepared to petition our IRB committees asking for a review and examination of the cultural preparedness of researchers engaging in research with human subjects. Our community should prepare suggestions to HHS on amending the Belmont Report and expanding the Common Rule to be more inclusive in its language, demonstrating the application of action research's impact on public policy.

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