



The SAGE Encyclopedia of Communication Research Methods

Vulnerable Groups

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Vulnerable groups involve human samples considered particularly susceptible to coercion or undue influence in a research setting. A vulnerable group includes persons who may be incapable of understanding what it means to participate in research and/or who may not understand what constitutes informed consent. Individuals considered vulnerable may, for various reasons, have a diminished capacity to anticipate, cope with, resist, and/or recover from the impact of a natural or man-made hazard. Vulnerable groups may also consist of individuals who are unable to care for themselves and/or may have an increased chance of suicide, self-harm, or the likelihood of harming others.

Researchers' assignment of vulnerable group status is both dynamic and relative, because the nature of those groupings is culturally dependent and those labeled as vulnerable are perceived as being in danger, at risk, under threat, susceptible to problems, helpless, and/or in need of protection or support. A situation that makes one person vulnerable may not make another person vulnerable. Being identified as a vulnerable group participant may also overlap with being identified as a victim or a troubled or troublesome individual.

Groups considered vulnerable can vary across academic disciplines, based on the frequency of practitioners' or researchers' interactions with those characteristics being studied. However, a nonexhaustive list of groups considered vulnerable across many human-research fields include children, the elderly, single parents, people with disabilities, ethnic minorities, those who are mentally disabled, asylum seekers and refugees, prisoners, pregnant women and fetuses, addicts, individuals with little social support, patients with an acute illness or chronic pain, victims of intimate and other forms of violence, and those who are homeless, economically disadvantaged, poor, illiterate, or unemployed. Some scholars argue that even students used as study participants are vulnerable if their research participation in a specific study (without reasonable alternatives) is mandatory for class credit.

This entry discusses the types of vulnerable groups, provides examples of inappropriate handling of vulnerable groups for research, and presents guidelines for protecting vulnerable groups during research studies.

Identifying Vulnerable Groups

Clearly, there are many different types of vulnerability that contribute to vulnerable group status. One type is the innate/personal, defined by characteristics unique to an individual person that may be sensitive. For example, innate/personal vulnerabilities may include psychological issues, such as anxiety disorders, Alzheimer's disease, and autism, or issues affecting self-esteem, such as obesity, illiteracy, or nonstandard appearances. Another type of vulnerability includes structural/contextual/environmental factors, or circumstances that lead to a group status assigned by a culture or society. Being homeless, using particular drugs, being a (legal or illegal) sex worker, or living in a war-torn country are examples of external vulnerabilities determined by the structural norms or environmental factors in a given culture.

Vulnerability may depend not only on how a cultural label is employed but also on how the participants themselves perceive their vulnerable status. Emic vulnerabilities are those for which participants possess particular self-awareness. They are aware that their group status or identity is a stigmatized (or otherwise sensitive) one. Emic vulnerabilities may be based on any number of internal or external contributing factors (e.g., mental illness, intimate violence). Etic vulnerabilities, conversely, are those for which the participants themselves may not be aware of their vulnerable status or may not personally identify with the group label that others

consider sensitive. In research contexts, etic vulnerabilities are often based on researchers' identification of a particular demographic variable or group status that has been associated with health problems or social risks in previous research. For example, being a member of a denigrated caste or living below the poverty level are assumed to be stigmatizing situations and, thus, labeled as vulnerable. Ultimately, vulnerability is shaped by a number of intersecting influences such as individual perceptions, situations, and social, historical, political, and cultural factors.

Being considered a vulnerable group can also vary based on which theoretical perspective the researcher privileges. For example, a feminist approach to protecting vulnerable groups would assert that in a primarily patriarchal society, women are more vulnerable than men, whereas a researcher with a Marxist perspective would opine that workers in low-paid jobs are a vulnerable group as a result of capitalism. Clearly identifying what a vulnerable group is can be further complicated by the fact that group members have multiple identities and lack homogeneity, and their membership may be transient.

Vulnerable Groups in Research and Resulting Safeguards

The Tuskegee Case

One well-known example of an inappropriate handling of a vulnerable group is that of the Tuskegee Experiments. During the period of 1932–1972, the U.S. Public Health Service conducted a study on syphilis among 600 African American males (400 with the disease and 200 without the disease) living in the countryside of Tuskegee in Macon County, Alabama. The researchers informed participants, who were mostly poor and uneducated, that the treatment (i.e., aspirin, spinal taps, and known ineffective tonics) they were receiving would help cure their syphilis. However, despite the discovery of an actually effective treatment early on in the study (penicillin in 1940), over 400 men remained intentionally untreated with any effective means. Members of this vulnerable group were not told they were participating in an experiment looking at the long-term effects of the disease and were further uninformed that effective treatments were being withheld. Years later, as a result of the experiment, Senate hearings were held, lawsuits filed, and new rules for medical and scientific research were required to be implemented. One aspect that came out of this new legislation was a clear mandate among human subjects researchers that protection for vulnerable groups should be prioritized. In 1997, President Bill Clinton apologized to the remaining living men and to the African American community. Nonetheless, “Tuskegee” is still used as a case example for explaining the importance of scientific research review and monitoring, especially when using vulnerable populations.

The Bangladesh Refugee Case

Another case illustrates the importance of researchers' awareness that harm can occur to vulnerable groups at any stage of the research process—in recruitment, during research, after the study is concluded, and when results are published. A study conducted with members of a refugee camp in Bangladesh illustrates this point. In this case, the researchers were seen by the study participants (i.e., the refugees) as having the power to effect change in their political and living status. After the study was completed, a number of aftereffects were seen. Participants approached the researchers seeking their help and assistance for families who were struggling within the camp system. The stories participants provided in the study and afterward to the researchers—of their neglect and the mismanagement of resources by the

very institution that was also protecting them—resulted in official repercussions to this vulnerable group for their perceived breach of confidence after the researchers left. In addition, the criminal elements in the camps also threatened and punished them for their apparent favoritism by researchers. As a result of this research project, 100 families had to be relocated due to these unforeseen ramifications; this relocation may have benefited these families, but left others in the camp continuing to suffer because of what had been revealed. This example shows that researchers need to be careful when publishing their data without consideration of the potential impacts of the communities or individuals involved. Vulnerable populations may not possess a full understanding of what informed consent constitutes and may be surprised and displeased to see themselves on film, quoted in articles, or broadcast publicly.

Guidelines for Protection of Vulnerable Group Participants

The U.S. Safeguarding Vulnerable Groups Act 2006 provides clear criteria for what constitutes a vulnerable adult. Anyone may be considered a vulnerable participant if he or she is in receipt of health or social care, lives in sheltered housing, requires assistance in the conducting of their affairs, resides in prison or is in contact with probation services, is detained under Immigration Act power, or is involved in any activities targeting vulnerable adults (e.g., education and training). These criteria were established to protect those who have no other legal access to redress in cases of grievance.

When using a vulnerable group sample, it is important and ethical for a researcher to provide appropriate and additional safeguards for participant well-being. The majority of universities and organizations conducting research have Institutional Review Boards that review and approve research proposals before researchers are allowed to pursue the research project. Because much communication research involving human subjects is considered a social science, the communication discipline adopts the safety and research guidelines established by the American Psychological Association, particularly when asserting that all participants must possess decisional capability when granting consent to take part in a research study. A member of a vulnerable group must be able to provide informed consent, although sometimes the individual may be capable of providing this consent and at other times someone else must provide that consent for the individual. When working with children, mentally disabled, or elderly individuals, it is necessary for researchers to understand what this entails.

Decisional capability is determined when a person provides evidence that he or she has the ability to (a) understand that he or she has a choice, (b) understand relevant information, (c) appreciate the situation of the study and its likely consequences, and (d) rationally manipulate the information presented to him or her. Highly vulnerable groups, such as those who are mentally disabled or elderly with dementia or Alzheimer's disease, may require a professional assessment of their actual ability to self-consent based on these four aspects. In other cases, less formal procedures may suffice (e.g., a legal guardian or parent grants consent on behalf of another).

When working with the aforementioned vulnerable groups, there are particular steps a researcher should take to gain "true" informed consent. First, an attempt should be made to gain consent directly from the participant. If the participant is unconscious or lacking in decision-making capability, then, the researcher should document his or her observations in the research record and medical records, and then gain surrogate consent from a guardian. If the researcher finds the participant is of questionable decisional capability but not unresponsive, the researcher can describe the research to the participant, document the

assessment of the participant's decisional capacity relevant to the information relating to the study, inform the participant of the intent to obtain the surrogate's consent, and gain assent (i.e., not legally binding approval or "consent" to participate) from the participant. If the participant expresses resistance to the intent to get a surrogate's approval or does not assent to participate in the study, then the researcher should exclude the participant from the study. Finally, if assent and consent are both obtained, the researcher should document this fact. Following these steps when working with a vulnerable group participant ensures that an ethical research process has been followed.

Children are also considered a highly vulnerable group and because of the focus on family communication, researchers in the communication discipline often find themselves wanting to use children as participants; therefore, special consideration is necessary when attempting to gain consent. When a researcher approaches children, he or she must first help the child understand, in a developmentally appropriate manner, the purpose of the study. Second, the researcher should disclose the nature of the study and what the child is likely to experience, such as types of questions to be asked and about what topic. Third, the researcher should assess whether or not the child understands the information that has been provided and if so, then secure the child's willingness to participate (i.e., assent). Regardless of whether the child chooses to participate, the parent or legal guardian still needs to sign the informed consent form on behalf of the child.

Many researchers find themselves using a vulnerable group population because the specific vulnerability is what requires exploration. For example, research may be needed to understand the vulnerability and address the treatment of, improve conditions for, or change policies on behalf of a particular condition. When choosing a vulnerable group to research, the researcher must adequately justify and provide detailed safeguard measures to protect the vulnerable individuals; anticipated benefits that clearly outweigh potential risks must also be clearly documented. All potential risks and costs associated with vulnerable groups should be offset by direct and tangible benefits to those who do choose to participate.

The ethical standards of the researchers are even more important when working with a vulnerable group sample, as compared to a nonvulnerable sample. For example, researchers must take even greater care in conducting their professional work with integrity and must respect the rights and dignity of those involved and who are affected by their research. Researchers must ensure the physical, social, and psychological well-being of those who take part in the study and must carefully interpret the findings of their research because of the impact it may have on the lives of those who will be affected long after the researcher leaves and the work is published. It is important to note that the principal investigator holds the ultimate responsibility for protecting the safety, rights, dignity, and welfare of all research participants.

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See also [Activism and Social Justice](#); [African American Communication and Culture](#); [Authorship Bias](#); [Communication and Culture](#); [Controversial Experiments](#); [Cultural Sensitivity in Research](#); [Cultural Studies and Communication](#); [Disability and Communication](#); [Feminist Analysis](#); [Latina/o Communication](#); [Underrepresented Groups](#)

Further Readings

Brandt, A. M. (1978). Racism and research: The case of the Tuskegee syphilis study. *The*

Hastings Center Report, 8(6), 21–29.

Higgins, Y. (n.d.). *Protecting vulnerable populations during research: Guidelines for safeguarding the health and welfare of children*. Retrieved June 3, 2015 from <http://www.cgirb.com/irb-insights/protecting-vulnerable-populations-during-research-guidelines>

Larkin, M. (2009). *Vulnerable groups in health and social care*. Thousand Oaks, CA: Sage.

Pittaway, E., Bartolomei, L., & Hugman, R. (2010). "Stop stealing our stories": The ethics of research with vulnerable groups. *Journal of Human Rights Practice*, 2(2), 229–251. doi:10.1093/jhuman/huq004

Reverby, S. M. (2009). *Examining Tuskegee: The infamous syphilis study and its legacy*. Chapel Hill, NC: University of North Carolina Press.

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