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Informed Consent and Cultural Relativism

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Lecture Topics

- ◆ Cultural relativism, moral relativism, and the implications for research ethics
- ◆ The implications of cultural relativism for obtaining informed consent in the international setting



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Section A

*Cultural Relativism,
Universalism, Absolutism?*

Cultural Relativism, Universalism, Absolutism?

- ◆ Is the requirement of informed consent based on American or Western notions of morality?
- ◆ Is the notion of “respect for persons” or “personhood” predominantly a U.S. or Western value?

“We conceive to a remarkable degree of the person in...individualistic terms, emphasizing...his or her rights, autonomy, self-determination, and privacy...In the American view, the individual person is seen as associated with...intimate others, but in comparison with non-Western societies, the range of the significant others is highly restricted. The notion of kinship extends only to biological relatives; it does not usually include kin-like friends or patrons and clients...Extended family and clans, and relations with the deceased and the unborn, especially ancestors and descendants, so interpersonally and metaphysically important in African and Asian societies, all play a minimal role in the conscious conception and life of the American individual”.

Ruth Macklin, *Against Relativism*, 1999

- ◆ Cultural relativism described by anthropologists in early 1900s—cultures had different practices; these were to be observed, not changed
- ◆ No word for “privacy” in Chinese (does this imply it is less highly valued?)
- ◆ Which practices are matters of “etiquette, ritual, or religion” and which have ethical content (Macklin)?

Macklin, 1999

- ◆ Important to separate differences in cultural norms from deciding whether differences are morally acceptable (Nazi example)
- ◆ Is it imperialistic to want to change differing cultural norms with ethics significance?
Related to human rights?

Macklin, 1999

- ◆ “A convincing argument against ethical relativism need not conclude that nothing is relative, only that certain types of actions or practices, chiefly, those that violate human rights, are not”

Cross-Cultural Notions of Personhood

- ◆ Respect for others may be valued, but less legalistic, less individualistic notion
- ◆ “Western philosophy has a perennial obsession with the concept of a person, and more importantly with criteria for personhood that would clearly segregate those entities worthy of moral consideration from those without or with less moral worth” (Tangwa, HCR, 2000)



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Section B

Cultural Relativism and Informed Consent

What Is the Relevance of this to Informed Consent?

- ◆ Should traditional means of decision making be included? Used exclusively? Ignored?
- ◆ Should consent be obtained from communities rather than from individuals? In addition? First?
- ◆ Should men be approached to enroll their wives in research where men make women's health care decisions?

Practical Considerations in Conducting Informed Consent

- ◆ Speak different languages
 - No word for “research,” “privacy,” or “placebo”
 - Can true meaning be conveyed?

Practical Considerations in Conducting Informed Consent

- ◆ Convey unfamiliar concept (research, placebo)
 - What degree of understanding is required?
 - Does it depend on the level of risk of study or is it a universal requirement?

Practical Considerations

- ◆ Doctor admitting uncertainty is unfamiliar
- ◆ Signing of forms is legalistic, unfamiliar
- ◆ Signing of forms can be misunderstood
- ◆ Multiple ways to learn, to communicate information

“Solutions?”

- ◆ “Menu of methods” for informing persons
- ◆ Respect both / multiple traditions for decision making
 - Confused to be asked individually, after other routes accomplished

“Solutions?”

- ◆ Ethnographic work to determine what participants know/understand and how concepts are described

Challenges Remain

- ◆ How much understanding is enough?
- ◆ When is paternalism justified?
- ◆ Meaning of voluntariness to people who are oppressed?
- ◆ Taking the time to develop good procedures

Informed Consent: Other Considerations

- ◆ Informed consent is “necessary but not sufficient” for an ethical study, participants still expect protection
- ◆ Consent form vs. consent process
 - Consent process happens through discussion
 - The form is documentation of consent

Informed Consent: Other Considerations

- ◆ Consent happens over time
- ◆ Must be repeated, even informally, especially when misunderstanding is likely