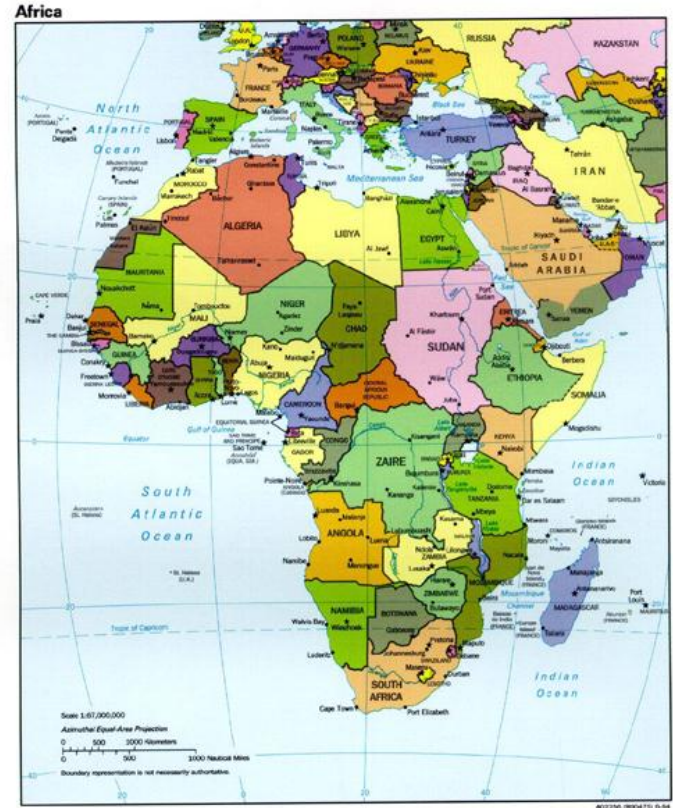


Research Communities in Africa: Dealing with reality.



Presented By

Rose Mwangi

Fundamental ethical principles



'Respect for Person

Beneficence

Justice

**1. Protection of rights,
safety and well-
being of trial
subjects**

2. Credible trial data



Objectives

- Highlight the differences between the Western and the African concept of the person and the implications for research and health care.
- Highlight some procedural challenges in informed consent
- Suggest alternative views and way forward.



Centrality of informed consent

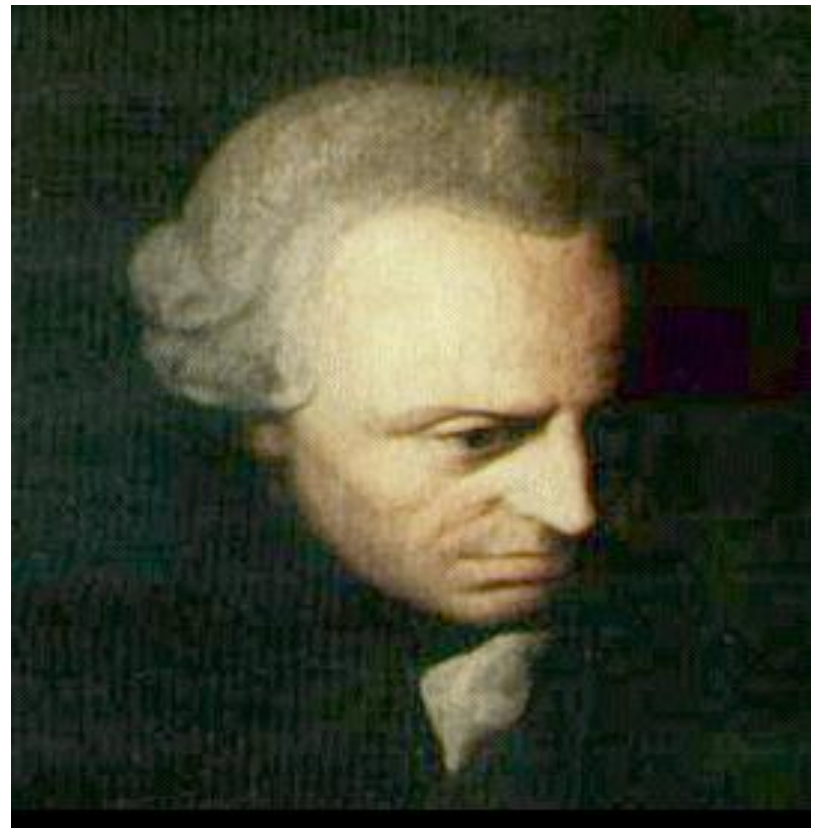
- Grounded in the interest in what it means to be human and how human nature must be protected.
- The “moral outrage” at Nuremberg: Not about “law” but rather violations of the fundamental dignity of “the human being.”
- Informed consent: Directly tied to human freedom, human dignity, and the fundamental nature of the human species.

Overview:

The Ethics of Respect

One of Kant's most lasting contributions to moral philosophy was his emphasis on the notion of respect

1724 - 1804



Kant on Respect

- “Act in such a way that you always treat humanity, whether in your own person or in the person of any other, never simply as a means, but always at the same time as an end.”

Immanuel Kant





Kant on Respecting Persons

- To respect people is to treat them as ends in themselves. He sees people as **autonomous**, i.e., as giving the moral law to themselves.



Treating People as Ends in Themselves

- Not denying them relevant information
- Allowing them freedom of choice



Autonomy

- The right to participate in and decide on a course of action without **undue influence**.
- Self-Determination: which is the freedom to act **independently**.
- Individual actions are directed toward goals that are **exclusively one's own**.



Challenges regarding procedural aspects of informed consent

- Currently ongoing discussion about the value and importance of particular approaches to informed consent in LDCs.
- Some of the interpretations and methods used in some western countries in obtaining informed consent might not be appropriate in Africa because of different cultural or social norms.



African culture and “autonomy”

- African cultures do not share many of the assumptions implicit in western autonomy base approach to bioethical deliberations
- African cultures take a community based approach rather than individual rights based approach
- Greater value and meaning rests in the interdependence of family, which transcends self-determination
- Centuries old tradition emphasises on the value of holistic view of a person that affirms the importance of the community, society and the family



Western concept of “self”

- Characterised as a substantive inner agency, capable of taking a first person stand point.
- Human self esteem seen as essentially independent of community
- The individual is seen as an architect of his or her own personality.
- The individual is therefore self contained.
- Children socialised to be independent



Western idea of autonomy

- Emphasis on personal choice
- Democracy and individual rights
- Informed consent now a legal issue
- To protect researchers and institutions



Western concept of autonomy

- A shift from communitarian values
- The role of the industrial revolution
- “inappropriateness” of old values to modern lifestyles
- The development of society based upon the “rights” of the individual.



Bantu People

‘In African culture the community always comes first. The individual is born out of and into the community, therefore will always be part of the community.’

The Notion of Ubuntu and Communalism in African Educational Discourse-
Elza Venter, *Faculty of Education, University of South Africa. Published
in Studies in Philosophy and Education 23 (2-3): 149-160, March,
2004 - May, 2004 Kluwer Academic Publishers*

Map showing
the
distribution
of the Bantu
people





Bantu people

- Bantu
- A large number of linguistically related peoples of central and southern Africa.
- A group of over 400 closely related languages spoken in central, east-central, and southern Africa, including Swahili, Kinyarwanda, Kirundi, Zulu, and Xhosa.



Bantu people

- Abantu - umuntu
- Vanhu - munhu
- Batu - mutu
- Andu
- Atu
- Mtu



Definition of Ubuntu

- A philosophy of life which represents personhood, humanity, humaneness and morality
- A metaphor that describes group solidarity where such group solidarity is central to the survival of communities with a scarcity of resources.
- The individual's existence is relative to that of the group.
- This is manifested in anti-individualistic conduct towards the survival of the group if the individual is to survive.
- Ubuntu is what separates men and women from beasts
- It is the potential of being human



African concept of the “self”

- Ubuntu characterised by
 - Group solidarity
 - Mutual support
 - De-emphasis on individualism
 - Respect for human dignity
- A person can only be a person through others
- An individual's existence is relative to that of the group



Ubuntu

- Emphasises human relationships in search for survival of society
- One is challenged by others to achieve self-fulfillment through a set of social ideals
- Notion of communalism exemplified in proverbs
 - Single tree cannot withstand wind
 - Knowledge is like the baobab tree-no single person can embrace it.
 - Kidole kimoja hakivuji chawa



Key social values of Ubuntu

- Group solidarity
- Conformity
- Compassion
- Respect
- Human dignity
- humanistic orientation
- Collective unity



Hierarchy & Ubuntu

- Chieftainships
- Headmen
- Communal hierarchical decision making
- Together we build - “Umoja ni nguvu” in decision making-democracy
- Ancestors



Ubuntu an asset

- Creates a natural feeling of belonging
- Promotes mutual trust and respect
- Encourages sharing
- Reduces stress and suicide rates



Ubuntu liabilities

- Pressure from extended family
- Perpetuates culture of dependence
- No competition but cooperation



Examples of Ubuntu in action

- Funerals – all welcome
- Marriage – extended family
- Divorce – ?
- Weddings – all welcome
- No appointments
- Extended family
- Totems - clan
- Villages - relatives
- Chieftainships – clans (“Mangi”)



Implications

What are the implications of these differences for research and health care?



Implications

Patient- doctor relationship

- Family members often take medical decisions on behalf of relative
- Patients place much trust in their family
- Loyalty, integrity, solidarity and compassion more important than autonomy



Trust

- Unquestioning attitude
- Physician / Researcher seen as authority figure
- Patient worry that non compliance may have serious consequences for family and community and self



Implications - African principles

- Obtaining written consent – no trust
- Community involvement
- Involvement of others in informed consent
- Involvement of community leaders in informed consent
- Involvement of women in research
- Benefits to the community
- Right to withdraw not meaningful
- Non questioning attitude



Is the involvement of others problematic?

- **OPINION-** 1. The involvement of others need not be discouraged in all cases
- It might even enhance the individual's ability to make his or her own choices and to give informed consent or informed refusal.
- Researchers need to acknowledge the close-knitness & the interdependence that exists among family members.
- 2- this reliance on others needs to be seen again as an added layer of protection. The paternalistic view which is adopted by many guidelines also apply.



Respect for culture :Implications for informed consent

- Respecting the culture is one of the implications of the fundamental principle of respecting persons.
- So informed consent should not to be seen a purely individual matter.
- It is associated with wider obligations to family.
- Respect participants request for time to discuss it with the family before they make the final decision.



New ethical principles for Africa

- Respect for culture
- Community involvement
- Community benefits



Conclusion (1)

- First person IC = best safeguard against exploitation
- Demonstrate respect for multi-person involvement
 - In procedural implementation of consent
 - Endorsement of community leader to enter community;
 - Respect participant's choice to involve others



Conclusion (2)

- distinguish between "permission" and "consent". Permission of the head is not individual's consent. Consent shouldn't be replaced by permission.



Conclusion (3)

The Agenda of Trust in Africa

- Research protections in Africa really are not about law or regulations.
- Real purpose is to protect the “agenda of trust” that is the non-negotiable foundation of the interaction between investigator and potential participant.
- Focus on process rather than on document



Conclusion (4)

- Research protection programmes should include some out reach programmes for the public who are the potential research participants.



Thanks for your attention