



ETHICAL ISSUES FACED BY **HOME BASED CARE** **ORGANIZATIONS**

Presented at

**Critical Research Ethical Issues in
the Era of HIV in Tanzania. On
14-15 April 2005 at The Courtyard
Hotel, Dar es salaam.**

Dr. Sabina Mtweve MD, MHP

Lecturer KCM-College

Home based Care Organizations D1.

- **What are they?**
- **What are the minimum competences for a NGO to qualify for Home based care?**
- **Do we have such organizations?**
- **If yes which are they?**

Home based Care

Organizations D1 cont...

- **If involved in research is there a need for Organizational Ethical committee?**
- **Should they have representatives in the institutional ethical boards? (Some suggest it does not help as those involved in such boards are biased just as the elites).**

Organizational Level.

Requirements of ethical understanding are:

- **Awareness of ethical dilemmas likely to arise in research and home based care organizational practice.**
- **An ability to formulate solutions in dialogue with peers, clients, mentors and others stakeholders.**
- **Sensitivity to participatory methods, inclusion of the organizations' members and especially clients**

Autonomy:

Definition:

- **Individual dignity, self-determination, and rights.**

Dilemma 2:

- **In situations where research is combined with care. Will a particular course of action lead to anyone especially the vulnerable being used as a means to an end without regard for their individual**



Understanding Research Implications.

- **Is there any benefit to the community the organization is serving?**
- **Does the research respond to a general community need? If so which community? or is it only for scientific knowledge, consumption of the elite?**

Beneficence

- **Doing the greatest good and balancing the risks and benefits.**

Dilemma 3.

- **Caregivers have an obligation to benefit the patient hence in research how is this handled? What does incentive mean to a poor sick person?**
- **Adequate coverage of injuries incurred and adequate compensation. What is adequate in**

Ethical Dilemmas Likely to Arise in Research and Organizations.

- **What is the research interest and who's interest?**
- **Understanding level of research implications and ownership of the implications. Who is responsible?**
- **Standards of care of the affected clients during the research.**
- **Post trial obligations by the**

Non-maleficence

- **Minimizing harm.**
- **Caregivers and research done in the community must avoid causing harm and strive to protect the patient from harm.**
- **Caregivers and Organizational community to be gate keepers.**

• They occupy a central point in

Helsinki 15.

- 15. *“Medical research involving human subjects should be conducted only by scientifically qualified persons and under the supervision of a clinically competent medical person. The responsibility for the human subject must always rest with a medically qualified person and never rest on the subject of the research, even though the subject has given*

DILEMMA 4.

- **Most home based care organizations do not have medically qualified persons working full time. Clients may not be well protected.**
- **After all what is a clinical medical research? Does the HAART research at home qualify as clinical medical research?**

DILEMMA 4 Cont...

- **What does medical mean in the era of holistic approach to health and its broad definition?**
- **In a setting where 70% of deaths possibly care as well take place in non clinical settings and home based care is encouraged?**



Ability to Formulate Solutions in Dialogue with Others and the Research Team.

- **On decisions on the power to collaborate ethically and scientifically.**
- **Setting memorandum of understanding or agreements on the roles, obligations to the study participants as well as to each other.**
- **Setting research priorities and limits**
- **Most organizations in Tanzania do not have such competences**

Helsinki 30

- ***“At the conclusion of the study every patient should be assured of access to the best proven prophylactic, diagnostic and treatment methods identified by the study”***

How can an organization fulfill this? It has no funds nor the power to convince the research team in order

Justice

- **Procedural: At times research has to be done in HBC organizations because that is where the patients can be found easily.**
- **At times it is a cheaper strategy**
- **Distributive justice of outcome: Yet the product of the research do not benefit the community**

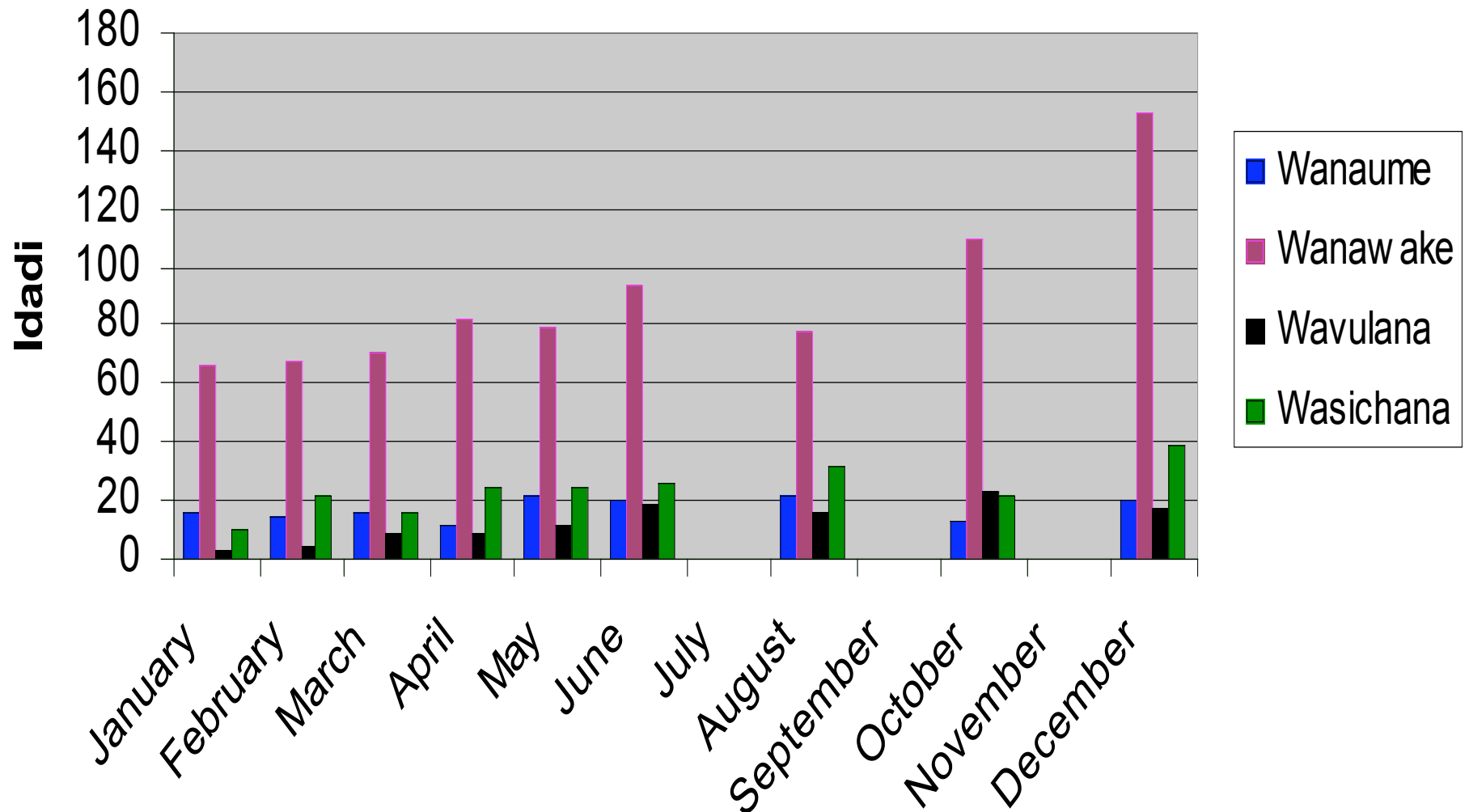


Justice Dilemma 5.

- **Research done in communities may have the effect of increasing the caring and counseling burden of home based care organizations overstretching resources and diminishing client satisfaction.**

Attendance at Center of Hope-KIWAKKUKI

Mahudhurio 1283 ya PLHA 2003





ACKNOWLEDGEMENT:

- **Clients workers members and co-worker at KIWAKKUKI and KCMC.**
- **To all who have facilitated this workshop.**



References:

- **WORLD MEDICAL ASSOCIATION DECLARATION OF HELSINK Ethical Principles for Medical Research Involving Human Subjects.**