HIV Research in International Settings: Ethical Responsibilities & Challenges

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Summary

• The `world` in which much HIV research is conducted is so different from the `world` of researchers that researchers may have limited comprehension of social implications of their work

• Insights into the ethical responsibilities & challenges of HIV research continue to evolve

• Wealthy countries do more to sustain poverty & poor health than they do to improve health

• New mind-sets about health & research are required to improve global health in 21st century
The Global Context for Research

• Wide (ening) disparities in wealth & health
• Medical research agenda (other than HIV) skewed away from the priorities of the poorest
• Mind-set of privileged researchers dominated by:
  – Biomedical/individualistic approach to health
  – Preference for new knowledge over old
  – Commercial `value` of research
  – Lack of insight into scale of the challenges for improving health in LICs
• Inadequate consideration of cross-cultural issues
  – Universalism & Relativism
• Complexity of Multi-Center Research Review
http://maps.grida.no/go/graphic/world_economy_cartogram
Philippe Rekacewicz, UNEP/GRID-Arendal, Vladimir S. Tikunov
HIV/AIDS Prevalence

Physicians Working

http://www.worldmapper.org/
Ethical Considerations Related to Provision of Care in (HIV) Research

• Central questions
  – Is there an obligation to provide care & prevention?
  – If so what is the source of the obligation?
  – Who should benefit?
  – What should be offered & for how long?

• Existing ethics guidelines provide broad principles on provision of care & Rx to participants in research

• They do not provide practical guidance on type, level & duration of Rx

• An overall agreement is emerging that as much as possible should be provided to participants in low-resource settings

UNAIDS 2007
Background & Progress

- Ongoing debates since Nuremberg Code 1948
- Escalating research on participants in LICs
  - Associated with complexity of HIV research in LICs
- Concern to avoid/reduce exploitation (vulnerable subjects)
- Progress over past decade regarding nature/extent of responsibilities to research participants & communities in LICs before, during & after clinical trials
  - Standard of care
  - Reasonable availability
  - Fair benefits
  - Ancillary care
  - Community engagement
  - Promoting social justice
  - Human development approach

Non-maleficence
Beneficence
Autonomy
Distributive Justice
Compensatory Justice
Social Justice
Relief of Oppression
Development
Two Overarching Principles

Research should play a facilitatory role in progressively improving health in host country (‘ratcheting upwards’) in broadest/most effective sense possible

Research should enable host country researchers eventually to undertake independent research in their own countries

Benatar, Singer. JME 2010
Clinical research is a morally complex activity. HD approach envisages clinical research as a unique social good whose power to advance the health needs of large populations is predicated on its fitting into a particular social division of labor with collaborations fostered between HICs & LMICs on terms of mutual respect and moral equality.
Evolution of Paradigms of Clinical Research

- **Researcher paternalism**
  - 1940s-1970s

- **Regulatory protectionism**
  - Mid 1770s - mid 1980s

- **Participant access**
  - Mid 1980s - mid 1990s

- **Community partnerships**
  - Mid 1990s onwards

Emanuel & Grady CQ 2007;16: 82-96

Next step: Promote Social Justice & Human Development
Universalism & Relativism

- There are some universal values
  - These are abstract & theoretical

- Moral reasoning is required for application
  - Moral reasoning requires consideration of context

- Contexts vary
  - In ways that may be morally relevant to the application of universal principles

- A middle ground can be found
  - That respects universals & acknowledges the relative/contextual

- Essential to build capacity of all involved parties
Conclusions/Challenges

• International collaborative research is conducted in a `world divided`

• Unless we alter our understanding of what is required ongoing divisions & disparities will be exacerbated

• We need to be more introspective about
  – our own lives
  – our roles & responsibilities in advancing knowledge & improving global health

• Multi-centre research review requires reconsideration
Conclusions/Challenges

Linking research to improvements in health & sustainable capacity building in research could contribute to a paradigm shift in thinking from research merely as a means of acquiring new knowledge towards a broader goal encompassing beneficial impacts on health, health care delivery & independence.

Further progress requires poverty reduction strategies & improvement in global health through a new paradigm of thinking & action that embraces more imaginative/innovative processes & links research to improving social justice.
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