

Ancillary care, the Declaration of Helsinki and the obligations of global research

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- 14. “The research protocol should describe arrangements for post-study access by study subjects to interventions identified as beneficial in the study or access to other appropriate care or benefits.”
- 33. Patients are entitled to share “other appropriate care or benefits.”

Ancillary care

- Care that researchers might provide to research subjects when they become unwell during, but not because of, participation in research.
- Particularly relevant in a developing world context where care may be not unavailable

Weijer and LeBlanc

- Researchers don't have a moral obligation to provide ancillary care.
- An obligation to consult, negotiate and gain the consent of the communities in the developing world. *The Journal of Law Medicine and Ethics*

UN Aids (2003): beneficence

...beneficence proposes to maximize benefits and minimize harm to subjects. The obligation to maximize benefits goes beyond the design of a trial and the conduct of a trial itself.

Weijer and LeBlanc respond

- An unrestricted moral obligation to “maximize benefits” leads to an unstoppable chain of demands upon researchers: if treating HIV for free is good, then, surely building hospitals and staffing them in perpetuity with free doctors and medical supplies is better. And if that is better, then making everyone not merely healthy but rich and happy is best of all. Right action, according to this view, comes with a hefty price tag.

UN Aids (2003): reciprocity

- With respect to the principle of *reciprocity*, subjects who become infected contribute importantly to the trial. Without such data, an efficacy trial could draw no conclusions about the intervention studied. People who contribute to this effort deserve something in return

Weijer and LeBlanc respond

- The determination of the efficacy of an HIV prevention intervention rests no more on those who become HIV infected than those who do not. Thus, the *contribution to the determination of efficacy* of those who do and those who do not become infected is equal. According to the principle of reciprocity, either no group is deserving of reward, or both groups are.

Thomas Pogge: A human rights based approach

- Diachronic vs subjunctive harms.

Thomas Pogge: A human rights based approach

- *First: responsibility for institutional harms is sensitive only to human rights deficits.*
- *Second, the human rights deficits must be causally traceable to a social institution.*
- *Third, responsibility for the deficit is assignable only to those who actively cooperate in designing or imposing the relevant institutions.*
- *Fourth, it's harming only if it is foreseeable that this order results in deficits.*
- *Fifth: rights deficits are reasonably avoidable.*
- *Six: avoidability must be knowable.*



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