Ethical Aspects of Studies on Populations Resident in Contaminated Sites

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Contaminated Sites and Health:
Recent Findings and the Way Forward
October 22, 2014 (Text in press, 2016)
Acknowledgement

THANK YOU
Taiwan Ecological Stewardship Association
AT WHOSE KIND INVITATION I AM VISITING TAIWAN

- Nancy Tzu-Mei Chen
- Yuping Chen
Personal Examples

- Contaminated fertilizer shipped from Texas, USA, to Bangladesh
- Sydney Tar Ponds, Nova Scotia, Canada
- Industrial Chemical Manufacturing complex under Soviet rule in Sumgayit, Azerbaijan
- In Italy ... much WHO work in this area
- Formosa No. 6 Naphtha Cracking Complex, Yun-Lin, Taiwan
Objectives

- Examples of contaminated sites

- Bringing professional ethics into the discourse on studying people in contaminated areas/sites

- Distinguishing contexts: between the need for more research and the need for action; and, between historically contaminated sites and sites experiencing ongoing contamination

- Providing a generic framework for ethical decision-making
EPIDEMIOLOGY

An applied science that bridges the basic sciences to human health and well-being

The science that informs health policy
“Industry’s offensive against the regulation of health and safety hazards uses academics to downplay or deny the seriousness of the hazards…”

Clayson and Halpern

J. of Public Health Policy

September, 1983
TEFLON?... LINKED TO BIRTH DEFECTS?

DON'T WORRY, THE ACCUSATION WON'T STICK.
Judge Miles W. Lord, 1982

On “Corporate Ethics and Environmental Pollution”:

“Corporations create 80% of our GNP. They, of all entities working, have the most potential for good or evil in our society.”

This was in 1982. Today it is surely more like 90%.
The ‘Four D’s’ - Institutional

Applied to scientists studying that which does not support the *status quo*:

- **Deny**
- **Delay**
- **Divide**
- **Discredit**

[Death – Meryl Streep in the movie *Silkwood*, 1983; Julia Roberts in *Erin Brockovich*, 2000]
THE GOLDEN RULE - adapted

- What is hateful unto you, do not do unto your neighbour
  
  *Hillel, Babylonian Talmud, Tractate Shabbat, 31B*

- Treat others as we would want them to treat us or our loved ones
  
  *Luke 6:31 and Matthew 7:12*

- Treat others justly so that no one would be unjust to you
  
  *From the Prophet Mohamed’s Last Sermon*

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- Do our level best
- Assert ourselves if we find that someone has done ill
Core Values & Mission Statements

- They provide the anchor for our activity and collective motivation … maintain, enhance, and promote health in communities worldwide … work to protect the public health interest above any other interest …
VALUES … CONTEXT
Deontological (i.e. duty-based)

In essence, the scientific ethic expects of scientists the duty to:

1. Use appropriate methods
2. Be objective
3. Be honest in reporting
4. Publish results - POSITIVE as well as NEGATIVE
5. Prohibit distortion in, for example:
   - Falsification of data
   - Biases inherent to study design
   - Proper analytical procedures
   - Objective interpretation
6. Do one’s own work:
   - Plagiarism
   - Acknowledge sources
   - Graduate students not to be exploited

GOOD ETHICS ⇔ GOOD SCIENCE
Classical techniques that skew results: from biased methods to junk science

- Linear reductionism without post-normal science to complement quantitative methods
- Under-powered studies
- Inadequate follow-up methods
- Inadequate follow-up time
- Contaminated controls
- Unbalanced discussion
- Selective disclosure of competing interests
The FUNDAMENTAL PRINCIPLES of BIOETHICS include:

RESPECT FOR AUTONOMY
- Requires respect for individual rights and freedoms (Also: Veracity & Fidelity)

BENEFICENCE
- Requires doing good / Consider consequences of interventions in people’s lives and of findings

NON-MALEFICENCE
- Requires doing no harm

JUSTICE
- Requires fair and equitable allocation (of risks & benefits) to all without discrimination
The FUNDAMENTAL PRINCIPLES of BIOETHICS include (under Justice):

- ENVIRONMENTAL JUSTICE
  - Who is taking the risks?
  - Who is deriving the benefits?

- THE POLLUTER PAYS
  - incentive to internalize costs
Primary Principles in Public Health

- Protect the most vulnerable in society (e.g., unborn, children, Inuit, frail elderly)
- Involve communities in our research (ensure community relevance of our work)
- Integrity in Public Health
  - Serve the public health interest above any other interest
A natural tension exists among all of the principles

We simply cannot perfectly satisfy all four principles fully on any single issue, but we must try to optimize each, transparently
Where does epidemiology fit into classical risk assessment?
Classical Health Risk Assessment

reductionist and linear in approach (US EPA 1960s)

1. Hazard Assessment
2. Vulnerability Assessment
3. Risk Evaluation
4. Risk Communication
5. Risk Management
What are we up against?

- What creates/drives misconduct in science?
- What tempts scientists away from the pursuit of truth?
- How does misconduct derail scientific discourse?
- How does misconduct influence public policy and hence population and global environmental health?
- Confrontation, and the challenge of speaking truth to power!
Making an Ethical Decision

2. Clarification & Evaluation

Ethical Principles:
- Beneficence
- Non-Maleficence
- Autonomy
- Justice
- Veracity
- Fidelity

One's Values/Beliefs

Values/Beliefs of Others

Value Conflicts

Social Expectations

Legal Requirements

Range of Actions/Anticipated Consequences

Professional Codes of Ethics

3. Action & Review
Generic problem-solving model for ethical decision-making

1. Gather all relevant information
2. Specify clearly all components of the identified ethical dilemma
3. Specify all options as possible courses of action
4. Select a single best alternative
5. Act and review
A Case Study of a bottom-up approach

CAUTION: ETHICAL IMPERIALISM
Whose role is it to deal with societal determinants of health?

The case of the Nigerian lead-poisoning epidemic by John D. Pringle and Donald C. Cole

The key relevant information (*i.e.*, biologic, economic, social, political, or ethical) and knowledge gaps, as well as the basis for these facts.

Identify the key stakeholders in the case and the most appropriate decision-maker(s) and/or legal authorities to approach the ethical issue, if applicable.

Identify the key values and *concerns* of the identified stakeholder(s), as well as any potential risks and benefits.
Identify the options available to the decision-maker, *including reasonable alternative courses of action, consideration of implications, and potential intended and unintended consequences.*

Suggest a resolution or decision to the case *by choosing the supported option, and justify the decision.*

How might the decision and/or action be evaluated?
And more going on internationally

A top-down approach to protections through constitutional amendments
24. Environment: Everyone has the right

a. To an environment that is not harmful to their health and well-being; and

b. To have the environment protected, for the benefit of present and future generations, through reasonable legislative and other measures that
   (i) prevent pollution and ecological degradation;
   (ii) promote conservation; and
   (iii) secure ecologically sustainable development and use of natural resources while promoting justifiable social and economic development.
And Other Countries too …

- Brazil, Columbia, Ecuador, Cuba, Andorra, Ukraine, France, India, China, Philippines, Papua New Guinea, Montenegro, Iraq, Kenya, Bhutan, …

- In 2012, David R. Boyd’s “The Right to a Healthy Environment Revitalizing Canada's Constitution”

- In 2014, David Suzuki Foundation campaign to amend Canada’s constitution to entrench the right to a healthy environment for all Canadians
Distinguish between community needs for ...

- More RESEARCH?
  OR
- More ACTION?
DISCUSSION