Health Disparities and Health Ethics

Narrowing the Gap Through Attention to Values and Ethics in Public Health Risk Assessment

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Empowering Communities in the Era of Health Care Reform
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Narrowing the gap

--- what gap?
The Eight Millennium Development Goals *(UN, 2000)*

1. **Eradicate extreme poverty and hunger**
2. **Achieve universal primary education**
3. **Promote gender equality and empower women**
4. **Reduce child mortality**
5. **Improve maternal health**
6. **Combat HIV and AIDS, malaria and other diseases**
7. **Ensure environmental sustainability**
8. **Develop a global partnership for development**
To start, we first must recognize:

- The non-sustainability of a world that operates currently with a 10:90 split / gap (where 90% of research funding goes to diseases affecting 10% of the global population)

- The existence of the Millennium Development Goals, set in 2000 amid a flurry of idealism and hope

- Disappointing movement towards achieving these 2015 goals
Think globally  ...
Act locally
Lenses through which we apply our training

- **Macro-level lens** (from 40,000 feet)
  - State, country or global-level

- **Meso-level lens** (from 1,000 feet)
  - Regional, city or community-level

- **Micro-level lens** (on the ground)
  - One-on-one-level
The LOCAL level
The Spirit Level: why great equality makes societies stronger

Richard Wilkinson and Kate Pickett (2010)


- Why Equality? The Evidence
  - Physical Health
  - Mental Health
  - Drug Abuse
  - Education
  - Imprisonment
  - Obesity
  - Social Mobility
  - Trust and Community Life
  - Violence
  - Teenage Births
  - Child Well-being
  - Equality Not Growth
  - Rich and Poor Countries
  - Equality and Global Warming
TED Lecture (17 minutes) and Transcript of interview

The Social Consequences of Inequality
May 13, 2012 by Theresa Riley

http://billmoyers.com/2012/05/13/the-social-consequences-of-inequality/
The MESO level
Why the affordable care Act’s individual purchase mandate is both constitutional and indispensable to the public welfare

- Briefing Paper (5 pages)
- Lawrence Gostin
The GLOBAL Level
The Joint Action and Learning Initiative (JALI)

Journal of the American Medical Association (JAMA), May 16, 2012

The article by Lawrence O. Gostin, O’Neill Institute Faculty Director, describes the Institute’s major global health initiative— the Joint Action and Learning Initiative on National and Global Responsibilities for Health (JALI)

JALI is a global network of civil society and academics seeking to secure a global health treaty -- a Framework Convention on Global Health (FCGH) -- to resolve today’s vast health inequities between and within countries

The FCGH would be grounded in the human right to health, achieve universal health coverage, establish far greater accountability, raise the priority of health in other legal regimes, and meet major challenges in global governance for health, such as poor coordination and inadequate financing

JALI seeks to ensure that the principles of an FCGH, including universal health coverage and the importance of people being able to claim and enforce the right to health, are central to the post-MDG agenda
Americans want a fairer society

ANDREW BEATTY
Agence France-Presse
WASHINGTON

Forget the socialist-bashing rhetoric and reverence for the filthy rich, when it comes to wealth distribution, Americans — even Republicans — would really rather live somewhere like Sweden.

According to a soon-to-be-published study by researchers at Harvard and Duke universities, Americans believe U.S. society is much more equal than it really is, and want it to be even fairer.

Business school professors Michael Norton and Dan Ariely asked 5,522 Americans about U.S. wealth distribution and how it should look if things could be changed.

"Respondents vastly underestimated the actual level of wealth inequality in the United States, believing that the wealthiest quintile (20 per cent) held about 59 per cent of the wealth when the actual number is closer to 84 per cent."

"Studies show current U.S. wealth inequality is near record highs, with the top one per cent of Americans estimated to hold around 50 per cent of the nation's wealth."

According to Norton and Ariely this tops "even the levels seen just before the Great Depression in the 1920s."

But when asked how they would like the United States to look, respondents picked "wealth distributions that were far more equitable than even their erroneously low estimates of the actual distribution."

In a blind test, about 92 per cent of respondents said they preferred a model closer to Sweden's wealth distribution to that seen in the United States.

The study's authors also reported a "surprising level of consensus" among different groups, with 92 per cent of Republican voters backing the Swedish model versus 93.5 per cent of Democratic voters, with the richest and poorest also voting along similar lines.

"All demographic groups — even those not usually associated with wealth redistribution such as Republicans and the wealthy — desired a more equal distribution of wealth than the status quo."

On average the top 20 per cent of earners were seen as holding just 32 per cent of wealth, less than the 84 per cent in reality.
Ethical dimensions of global climate change
November 6, 2007 (Courtesy J. Patz) -- Cartograms
Science is but one such pressure

--- HUMILITY AND EMPATHY FOR THE POLICY-MAKER
Influences and pressures

- From funding sources to peer review
- From the questions we ask through access to data
- From study design to data analysis and interpretation
- From dissemination to job security
Manufacturing Doubt

- D. Michaels, *Doubt is their Product*, 2008 (Oxford University Press)
- D. Davis. *The Secret History of the War on Cancer*, 2007 (Basic Books)
- By increasing uncertainty, the policy-maker’s ability to implement health policy is made all the more difficult …

→ *subversion and ambush of science*
The Four D’s applied to scientists studying that which does not support the *status quo*

- Deny
- Delay
- Divide
- Discredit
  - [Dismiss]
Be aware of forces at play that influence both science and policy.

... Great vigilance and personal integrity are required to change course
“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.
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.”
THE NORMAL RANGE OF HUMAN CONDUCT

VERY POOR

AND EVERYTHING

IN BETWEEN

DISHONEST

POWER CORRUPTS. ABSOLUTE POWER CORRUPTS ABSOLUTELY!

(HLord Acton’s premise)

NO ONE IS IMMUNE!
Definitions

ETHICS - The rules of conduct/behavior recognized in respect to a particular class of human actions or a particular group or culture.

SELF-REGULATED

MORALS - Principles or habits with respect to right or wrong.

LEGALLY ENFORCED
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 …
Why ethics in the professions?

- Keep ourselves on track, or keep our own house in order
- Socialize our students
- Professional accountability
  - According to norms of behavior
  - IN WHOSE BEST INTERESTS?
  - WHO IS TAKING THE RISKS?
  - WHO IS DERIVING THE BENEFITS?
THEORETICAL APPROACHES/MODELS

ETHICAL THEORIES

• Normative
• Utilitarian
• Deontological
• Egalitarian
• Relational
• Libertarian
• Virtue
THE DISCIPLINE OF ETHICS

RULES

PRINCIPLES

THEORIES/APPROACHES
Prescriptive codes

versus

Aspirational codes
THE TEN COMMANDMENTS

• Thou shalt have no other Gods before me
• Thou shalt not bow down before graven images
• Thou shalt not take the name of the Lord thy God in vain
• Remember the Sabbath Day and keep it holy
• Honour thy father and thy mother
• Thou shalt not kill
• Thou shalt not commit adultery
• Thou shalt not steal
• Thou shalt not bear false witness against thy neighbour
• Thou shalt not covet

Moses, Mount Sinai
The Buddhist Code of Moral Conduct

by Vajiranananavarorasa

The First Precept:
Abstaining from taking the lives of living beings

The Second Precept:
Abstaining from taking that which is not given

The Third Precept:
Abstaining from sexual misconduct

The Fourth Precept:
Abstaining from false speech

The Fifth Precept:
Abstaining from distilled and fermented intoxicants which are the occasion for carelessness which also includes drugs
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

• Do our level best

• Assert ourselves if we find someone else who has done ill
The Scientific Ethic*

A set of norms that define the scientific endeavor—an ethos that evolved gradually and organically.

PROFESSIONAL ETHICS embody some of these norms, but “The Ethic of Science” is more like the charter that makes science possible than like a law book that spells out the specific rules.

This ethic defines the boundaries that must be respected by those who wish recognition as part of the scientific community.

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
The FUNDAMENTAL PRINCIPLES of BIOETHICS include:

RESPECT FOR AUTONOMY

- Requires Respect for Individual Rights and Freedoms (voluntary vs. involuntary exposures)

BENEFICENCE

- Requires Doing Good - Consider consequences of interventions in people’s lives and of findings

NON-MALEFICENCE

- Requires Doing No Harm

JUSTICE

- Requires the fair and equitable allocation of risks and benefits to all without discrimination
- No hierarchy

- Constant tension among the four main principles

- Aim to maximize each of the four
Other public health principles

- Protect the most vulnerable in society
  - Beneficence
- Involve communities in our research
  - Respect for autonomy
- Serve the public health interest above any other interest
  - Beneficence and Non-maleficence

Always act with INTEGRITY
  - Beneficence & Non-maleficence
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
The FUNDAMENTAL PRINCIPLES of BIOETHICS include (under Non-maleficence and Respect for Autonomy)

**PRECAUTIONARY PRINCIPLE**

- where there is a risk from a certain agent, the presence of uncertainty shall not be used as a reason for postponing cost-effective measures to prevent such exposure
GUIDELINES versus CODES

• Normative statements that are aspirational versus prescriptive

• A “list” versus a “checklist”

• “List” provides a basis for discussion:
  • Context
  • Recognize tensions
  • Not for application as a “checklist”!
Ethics Guidelines

The International Society for Environmental Epidemiology (ISEE) approved its new edition Ethics Guidelines on April 25, 2012

Principles – their utility

- Normative basis for rational policy
- Transparency of collective values
- Accountability for actions taken
Character vs. Actions

Virtues do not replace ethical rules. Rather, an account of professional ethics is more complete if virtuous traits of character are identified, such as:
VIRTUES OF PROFESSIONALS

- **Humility** – Respect the input and opinions of others/Self-effacement
- **Fidelity** – Honor one’s commitments/Promote trust
- **Justice** – Act fairly
- **Patience** – Take time to hear others’ viewpoints
- **Industry** – Do your level best/Excel
- **Veracity** – Tell the truth/Be honest
- **Compassion** – Empathize
- **Integrity** – Demonstrate good moral character
- **Serve** – Protect the most vulnerable/Serve the public interest
- **Prudence** – Err on the side of caution/Demonstrate good judgment
Classical Health Risk Assessment –
reductionist and linear in approach

1. Hazard Assessment
2. Vulnerability Assessment
3. Risk Evaluation
4. Risk Communication
5. Risk Management
But, “applied ethics” is context-related
Libertarian Values
... in the USA

The individual’s right to “life, liberty and the pursuit of happiness”

Declaration of Independence
Benjamin Franklin, Thomas Jefferson,
... John Locke (1776)
Egalitarian Values
... in France

*Liberty, Equality, and Fraternity*

“If they cannot afford to eat bread, let them eat cake”

Louis XVI and Marie Antoinette
The French Revolution (1789-1792)
Communitarian values … in Canada

Greater focus on community through “Peace, order and good government”

Constitution Act
“Fathers of Confederation” (1867)
Distinguish between Rights and Duties
An application Issue
QUESTION ...

Is science value free?

OR

Is science value neutral?
Examples
A published work of relevance

Two Examples (from Weed 1997)

Meta-Analyses:

– Alcohol & Breast Cancer
– Induced Abortion & Breast Cancer
SAME PLANET, DIFFERENT WORLDS.
The Hill “criteria”. Is an observed association causal in nature?

- Strength of Evidence
- Consistency across studies
- Specificity of effects
- Temporality of effects
- Biological Gradient (dose-response)
- Plausibility of effects
- Coherence with other knowledge
- Experimental evidence
- Analogy based on experience
But, Hill cautions

- Broad interpretation of the evidence with respect to his “aspects”.
- Use as a guide to help answer if there is any other way to explain the set of facts before us.
- To not discount associations because there is insufficient evidence or understanding at one point in time.
- Causal judgments do not require perfect information and must be considered in the context of available knowledge and a responsibility to protect health.
“All Scientific work is incomplete – whether it be observational or experimental. All scientific work is liable to be upset or modified by advancing knowledge. That does not confer upon us a freedom to ignore the knowledge we already have, or to postpone the action that it appears to demand at a given time.”
Risk Perception – Context (1 of 2)

Risk Perception

My Karma Ran Over Your Dogma

RISK PERCEPTION

Shit happens. Confucius says, Shit happens. If shit happens, it is the will of Allah.

TAOISM

CONFUCIANISM

ISLAM

Let shit happen to somebody else. If shit happens, you deserve it. What is the sound of shit happening?

PROTESTANTISM

CATHOLICISM

ZEN
Risk Perception – Context (2 of 2)

What is this shit?
I don't believe this shit.
Why does this shit always happen to us?

AGNOSTICISM
This shit has happened before.

ATHIEISM
If shit happens, it isn't really shit.

JUDAISM
Ask me into your house, and I will tell you why shit happens.

HINDUISM

BUDDHISM

JEHOVAH WITNESS

* ORIGINAL CONCEPT BY UNKNOWN
The Challenge

オススメ

Who takes the risks while who derives the benefits? Or, whose interests are being served in this policy?

Burden of proof of safety lies on the proponent, or on Joe and Jane Public?
TAKE HOME MESSAGES

- Uncertainty IS inherent to science
- Science strives to be value-neutral / -free, but the human instrument is not
- Look first to ourselves, because causal inference is a function of who it is that is making the inference which, in turn, is a function of how we apply our scientific methods
DISCUSSION