Health Disparities and Ethics

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

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Fall 2018 Course - Disparities in Health in America:
Working Toward Social Justice
University of Houston-Downtown Campus

Televised to the University of Texas Medical Branch at Galveston, the University of Florida Health, Florida A&M University, the University of Miami, the University of Texas at Austin and Temple University Health System.

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Outline

- The widening gap and what it means
- Professional roles and obligations in protecting the public interest
- Context for values, ethics and virtues
- How these things relate to risk assessment
- Humility and professional judgement
- Who takes the risks while who derives the benefits? In whose best interests?
A Disclaimer

I appear before you today, not from a position of self-righteousness saying that I know all of the answers, but rather to prompt you to be more aware of the questions to which you may wish to seek the answers.

Colin L. Soskolne
Conformist Thinking: our local contexts

- Leadership requires the ability to think beyond the constraints of the dominant paradigm … *i.e., the narrative of our lives*

- We are raised to believe that certain norms are correct; well, consider that: we have often been misled

Narrowing the gap

--- what gap?
The Eight

Millennium Development Goals (MDGs) (UN, 2000)

Replaced by the 17

Sustainability Development Goals (SDGs) in January, 2016
Sustainability Development Goals (SDGs)
17 GOALS; 169 TARGETS AND INDICATORS

They are based on six essential elements:

- “DIGNITY, PEOPLE, PROSPERITY, OUR PLANET, JUSTICE, AND PARTNERSHIP.”

Many development experts have noted the ambitious sweep of the goals, which include:

- ENDING POVERTY IN ALL ITS FORMS EVERYWHERE
- ENDING HUNGER
- ACHIEVING GENDER EQUALITY
- ENSURING HEALTHY LIVES AND PROMOTE WELL-BEING FOR ALL AT ALL AGES, AND
- ENSURING ACCESS TO AFFORDABLE, RELIABLE, SUSTAINABLE, AND MODERN ENERGY FOR ALL.
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 Millennium Development Goals (MDGs) were set in 2000 amid a flurry of idealism and hope … with 2015 the date for their achievement

- However, disappointing movement towards achieving the 2015 goals
“Think globally, Act locally”

... made famous by René Dubos

Lenses through which we apply our training

- **Micro-level lens** (on the ground)
  - One-on-one-level

- **Meso-level lens** (from 1,000 feet)
  - Community, Regional, City, State, Country-level

- **Macro-level lens** (from 40,000 feet)
  - Global-level
The MICRO (one-on-one)–level
Those influences that determine our context

The narrative that defines us and how we apply our skills in that context

Epidemiology has its focus on public health, and not so much on individual health
The MESO-level
The Spirit Level: why great equality makes societies stronger

Richard Wilkinson and Kate Pickett (2010)

- https://www.youtube.com/watch?v=AFOEe6M2VT4

- Why Equality? The Evidence
  - Health
    - Physical Health
    - Mental Health
    - Drug Abuse
    - Obesity
  - Children and Social Mobility
    - Child Well-being
  - Education
  - Teenage Births
  - Social Mobility
  - Sustainability and Development
    - Global Warming
    - Foreign Aid and Global Peace Index
  - Crime
    - Imprisonment
  - Violence
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/
Wealth Inequality in the USA

A 6-minute video that demonstrates the ever-widening income disparities in the USA, showing how Americans think *versus* the reality of income disparity in America:

http://mashable.com/2013/03/02/wealth-inequality/

by Charlie White, March 2, 2013

Canada is becoming similar, where the richest 86 people have as much wealth as the poorest 11.4 million of some 35 million people in Canada …

http://www.thestar.com/business/2014/04/03/canadas_riches_86_people_have_as_much_wealth_as_the_poorest_114_million.html
Canada’s wealthiest win as income gap widens

The Canadian Press

OTTAWA — A new OECD paper shows Canada is among the worst in the developed world in terms of the widening income gap.

The analysis shows income inequality has grown in most advanced economies represented in the Organization for Economic Co-operation and Development over the past three decades, but the United States and Canada are near the top in terms of growth and in absolute terms.

The OECD says the top one per cent of Canadian pre-tax income earners captured 37 per cent of the overall income growth between 1981 and 2012, and now account for 12.2 per cent of the country’s total annual income.

In the U.S, the top one percenters captured 47 per cent of the total income growth in the country during the period — and now share one-fifth of the country’s pre-tax income.

Meanwhile, incomes among the poorest households have not kept pace with overall income growth, the OECD says, and in fact stripping away the top one percenters would leave overall income growth considerably lower in many countries.

This is why the majority of the population can’t reconcile their countries’ economic growth rate with improvements in their incomes, the OECD report speculates.

The OECD data shows income disparities, while growing in most of the 34 economies it tracks, varies greatly from country to country, with little correlation to the economic performance during the period.

For instance, Sweden, Norway and Finland — three rich countries — remain relatively egalitarian even though they had among the biggest jumps in income inequality during the period.

The top one percenters only accounted for between seven and eight per cent of total income in those countries in 2012.
While non-whites, younger people and people in other countries are seeing falling death rates, a new study shows the reverse is happening for white men and women in the US aged 45-54. Proceedings of the National Academy of Sciences.
Reasons

- Suicide
- Drug and alcohol abuse
- Declining mental and physical health
- Financial Stress
Marmot Makes The Case Yet Again For Social Determinants Of Health As The “Causes Of The Causes”

http://www.epimonitor.net/Marmot-on-Social-Determinants.htm

- Social Inequalities Drive Health Inequalities
- The Australian Broadcasting Corporation’s annual Boyer Lecture series featured prominent epidemiologist and public health researcher Sir Michael Marmot delivering four lectures entitled Fair Australia: Social Inequalities and the Health Gap. (September, 2016)

http://www.abc.net.au/radionational/programs/boyerlectures/
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.
The Canadian “advantage” in health insurance?

- Andre Picard – award-winning journalist, the mythology of a Canadian advantage

- Podcast (Canadian Broadcasting Corp.)
  
The MACRO- (global) Level
Global Change and Public Health: Addressing the Ecological Determinants of Health

It is adds “ecological determinants” as a critical factor to the “social determinants”.

https://www.cpha.ca/sites/default/files/assets/policy/edh-discussion_e.pdf
The Joint Action and Learning Initiative (JALI)

- Lawrence O. Gostin, O’Neill Institute Faculty Director

- 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. JAMA (2012)

- 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

PUBLIC POLICY

PROFESSIONAL INTERESTS

PERSONAL/SELF-INTEREST

CULTURAL INTERESTS

RELIGIOUS INTERESTS

FOREIGN INTERESTS

CORPORATE / MULTINATIONAL BUSINESS INTERESTS

INTERNATIONAL AGENCY & PUBLIC INTERESTS

NGO - STAKEHOLDER INTERESTS

MINORITY INTERESTS

SECTORAL INTERESTS

MEDIA INTERESTS

SCIENCES

EDUCATION

SOCIAL

HEALTH

ECONOMIC

ADVOCACY
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


- Davis. *When Smoke Ran Like Water: Tales of Environ Deception*, 2002
  *The Secret History of the War on Cancer*, 2007
  *Disconnect: The Truth About Cell Phone Radiation*, 2010


*By fomenting uncertainty, the health policy-maker’s role is undermined … → the subversion and ambushing of science*
Merchants of Doubt: How a Handful of “Scientists” Obscured the Truth on Issues from Tobacco Smoke to Global Warming

Also made into a movie...
Released in 2015
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.
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.”
THE NORMAL RANGE OF HUMAN CONDUCT

VERY POOR  ←  AND EVERYTHING

DISHONEST  ←  IN BETWEEN

HONEST  →  VERY GOOD

POWER CORRUPTS. ABSOLUTE POWER CORRUPTS ABSOLUTELY!

(Lord 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
developed for professional organizations

- 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?

- To keep ourselves on track, or to keep our own house in order
- To socialize our students
- For 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
- Honor 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 neighbor
- Thou shalt not covet

Moses, Mount Sinai

https://scripturememory.com/10commandments?gclid=EAIaIQobChMI4biz0JDP3QIVDFYMCh0DQAudEAAYASAAEgL-rPD_BwE
The Buddhist Code of Moral Conduct

by Vajirananavarorasa

*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 neighbor
  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 \( (\text{voluntary vs. involuntary exposures}) \)

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


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
The 1965 Hill aspects ("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

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1898525/?page=6
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.
Hill concludes ...

“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.”
Examples
QUESTION ...

- Is science value free?

OR, said another way:

- Is science value neutral?
A published work of relevance

Two Examples (from Weed 1997)

- Meta-Analyses:
  - Alcohol & Breast Cancer
  - Induced Abortion & Breast Cancer
SAME PLANET, DIFFERENT WORLDS.
Risk Perception – Context

My Karma Ran over Your Dogma

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RISK PERCEPTION

APPENDIX 3

TAOISM

Confucianism

Islam

Let shit happen to somebody else.

If shit happens, you deserve it.

What is the sound of shit happening?

Shit happens.

Confucius says, shit happens.

If shit happens, it is the will of Allah.

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

ATHIEISM

JUDAISM

This shit has happened before.

If shit happens, it isn’t really shit.

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

HINDUISM

BUDDHISM

JEHOVAH WITNESS

*Original concept by unknown*
The Challenge

- Who takes the risks while who derives the benefits? Or, whose interests are being served in this policy?
- Does the burden of proof of safety lay 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