Healthcare Inequalities, Ethnography, & Christian Social Ethics

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4 Basic Aims

- Introduce Myself & Ethnography
- Offer an Overview of Health & Healthcare Inequalities
- Discuss My Work: Healthcare Inequalities & Ethnography
- Highlight Steps in Research Design
Part One

Introducing Myself & Ethnography
3 Formative Moments

- Growing Up & Interdisciplinary Studies

- Master’s Work: need to engage people as much as books

- M.Div. Bioethics & Chaplaincy Internship
  Work with Latino Patients
  Beginning Awareness of Health Inequities
Defining Ethnography

- Qualitative research method, historically-rooted in anthropology
- May incorporate various strategies (e.g. participant observation, focus groups, individual interviews)
- A disciplined way to listen to a particular situation or context
Contrasting Two Methods

Qualitative

- Inductive
- Goal: To develop a “thick description” (Geertz) of a culture, community, group, etc.
- Stories

Quantitative

- Deductive; testing of a hypothesis
- Goal: To arrive at a universalized/highly generalized finding
- Statistics
• BOTH are needed & valid modes of research

• Can be used in combination with each other

• Nuanced work TRIANGULATES data a.k.a. stories & statistics
Ethnography as:

A Way to Pay Attention

A way to discover truth revealed through embodied habits, relations, practices, narratives, & struggles

A way to take God’s incarnation seriously
“Good”* Ethnography

a.k.a. What I tell folks in Christian Theology/Ethics who are interested in doing this kind of work

Exemplars in the new book – see chapter by Whitmore, Reimer-Barry, Browning, etc.

* “Good” = nuanced & responsible
7 Key Qualities

1. RIGOROUS
   Takes the ethnographic work as seriously as biblical exegesis

2. HUMBLE
   The Researcher is NOT the expert
   Makes modest, defensible claims in light of findings

3. CRITICALLY SELF-REFLECTIVE (Reflexivity)
   “Checking ourselves” & open to being changed by what one witnesses
4. ATTENDS SERIOUSLY TO POWER DYNAMICS

5. COLLABORATIVE

6. ACCOUNTABLE
   Permissions, IRBs, Informed Consent
   Feedback Loops & What is done with the work
   Careful, thoughtful representation of people

7. AUDACIOUS
   Bold to claim that there is theological and ethical knowledge embedded in particular lives and places
Part Two

Snapshot of U.S. Inequalities
U.S. Healthcare Costs

Per 2011 data:

Annually, the U.S. spends $2.5 trillion (nearly 18% of the GDP; over $8,000 per person) on healthcare

*Double what any other industrialized country spends*
U.S. Healthcare Costs

Harvard 2009 Study: 62% of all personal bankruptcies were caused by health problems and 78% of filers had insurance

In 2010, workers paid $4,000 out of pocket for healthcare (Kaiser Family Foundation)

Since 2000, average premiums for family coverage has increased 114% (Kaiser Family Foundation)
How We Compare to Peer Nations

2008 Commonwealth Fund: The U.S. scored a 65 out of a possible 100—across 37 core indicators of performance

2011 IMF data: U.S. has the highest infant mortality rate of 33 advanced economies

U.S. spends far more healthcare dollars on administrative costs (22 %) than peer nations

(Source: Sick Around the World)
How We Compare to Peer Nations

2009 *Health Affairs*: U.S. ranked at the bottom of 19 peers in terms of preventable deaths (e.g. diabetes, epilepsy, stroke, pneumonia.)

The U.S. has more preventable deaths than countries such as Portugal, Ireland, Norway, Italy, Japan, Germany, England, Spain, etc.

“Up to 101,000 fewer people would die prematurely in the U.S. if the U.S. could achieve leading, benchmark rates”
The U.S. Un- & Under-Insured

The CDC:
Almost 59 million Americans went without health insurance for at least part of 2010

2009 U.S. Census Data:
50.7 million (16.7% of total pop.) were uninsured, including 7.5 million children

Sources:
The Centers for Disease Control (CDC): http://www.reuters.com/article/idUSTRE6A905U20101110
The U.S. Census Bureau: http://www.census.gov/prod/2010pubs/p60-238.pdf
Number of Uninsured Now Exceeds Cumulative Population of 24 States Plus the District of Columbia

Total number of uninsured in 2004 exceeds the population of these 24 states and the District of Columbia.
Who Are these People?

- Over 75% are in a working family
- 81% are U.S. citizens
- Darker-skinned communities are disproportionately represented among the ranks of the uninsured

U.S. Racial-Ethnic Compositions 2009

- 32% of Latinos (16 mill) are uninsured
- 21% of Blacks (8 mill) are uninsured
- 17.2% of Asians (2.4 mill) are uninsured
- 12% of Whites (24 mill) are uninsured

Latinos make up 15.8% of the total population.
Blacks make up 12% of the total population.
Asians make up 4.5% of the total population.
Whites make up 65% of the total population.

U.S. Census 2009 data
2009 AHRQ Report

The 2009 report finds that disparities related to race, ethnicity, and socioeconomic status still pervade the American health care system.

Although varying in magnitude by condition and population, disparities are observed in almost all aspects of health care, including:

- Across all dimensions of health care quality: effectiveness, patient safety, timeliness, and patient centeredness.
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- Across all dimensions of health care quality: effectiveness, patient safety, timeliness, and patient centeredness.
• Across all dimensions of access to care: facilitators and barriers to care and health care utilization.
• Across many levels and types of care: preventive care, treatment of acute conditions, and management of chronic diseases.
• Across many clinical conditions: cancer, diabetes, end stage renal disease, heart disease, HIV disease, mental health and substance abuse, and respiratory diseases.
• Across many care settings: primary care, home health care, hospice care, emergency departments, hospitals, and nursing homes.
• Within many subpopulations: women, children, older adults, residents of rural areas, and individuals with disabilities and other special health care needs.
Breast Cancer in Chicago

Black women are 73% more likely to die of breast cancer than their white counterparts

Source: The Chicago Tribune, 10/18/06
U.S. Racial-Ethnic & Socio-Economic Inequalities: Key Sources

The Kaiser Family Foundation (KFF)
http://www.kff.org/

The Commonwealth Fund

The Institute of Medicine (IOM)

The National Institutes of Health (NIH)

The Centers for Disease Control (CDC)

The Agency for Healthcare Research and Quality (AHRQ)
http://www.ahrq.gov/qual/qrd09.htm

The Robert Wood Johnson Foundation
Roots of Racial-Ethnic Inequalities

- Socio-economic Barriers (education, poverty, food desserts, geography, insurance etc.)

- Cultural Barriers (language, education, cultural & religious preferences)

- Tenacious Stereotypes and Potential for Bias
  - Intensified by time pressure, cognitive complexity, the culture of medicine, lack of cross-cultural trust and understanding, etc.
PART THREE

Highlight of My Own Work
“To Count Among the Living”

- Doctoral Studies & The Rev. Dr. Annie Ruth Powell
- A lesson in Humility

“We must learn to count the living with the same particular attention with which we number the dead”

-Audre Lorde
Quick Sketch of the Research

Qualitative Research Methods Writing Group at Columbia University

IRB Process

Scope/Design of the Study
Sophia’s Story

For Sophia’s story, and several others, please see my book:

*Women Ethics, & Inequality in Healthcare:*

“*To Count Among the Living*”

Palgrave MacMillian, (revised paperback edition, 2011)

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Audre Lorde
PART FOUR

The “Nitty-Gritty”: Steps in Research Design
1. Formulate a Research Question

What do you want to learn? With/from whom do you hope to learn?

Should give a solid sense of direction, but also needs to be open to revision as you learn more

The question needs to be both substantive & relevant

  e.g. Informed by community-expressed needs
2. Project Design: “Form Follows Function”

What kinds of materials will help you learn what you want to learn?

- Triangulate various kinds of pertinent data, e.g. historical, sociological, economic, Census, interviews, sermons, advocacy work, etc.

What strategies will foster learning & rapport?

- Options Include: Individual interviews, Focus Groups, Participant Observation, Participatory Action Research
3. Field Notes & Interviews

Notes:

- Immediate
- Thorough, detailed, concrete
- Self-Critical & Aware (reflexive)
- Protected

Recording & Transcribing Interviews

Lots to consider: Equipment, Rapport, Confidentiality, Danger of Objectification
4. Analysis

- Critically reflect on your mistakes, missteps, assumptions, and fumbling

- Feedback Loop: Check understandings and conclusions with participants when possible and appropriate

- Attend to the dissonances & disconnects—don’t try to create a “perfect picture” or force unity

- Synthesis of—Coding for—themes

- Humility in Claims & Avoid Romanticizing/Objectifying
5. Writing, Publishing, Sharing

- How and with whom will you share this work?
- Will the collaborators have access to it?
- How have you been changed by this work?
- How have you benefited from it?
- What new theological/ethical endeavors or projects grow out from it?