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GRAND CHALLENGE:

The Relationships of American Values and Beliefs to 21st Century Health, Practice and Health Care Policy

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Abstract: This research explores the recent rapid changes in the health of Americans – particularly the rise in diabetes and obesity – and in the institutions charged with restoring or maintaining health. Beginning with a case report synthesized from several patients who presented to rural Arizona emergency rooms over the course of a year, this paper proposes a series of ethnographies designed to address questions raised by the occurrence of rare, highly lethal Fournier's gangrene among "working poor" diabetic women. Drawing subjects from a socioeconomic cross-section of Americans, researchers will observe daily life as well as patient-physician interactions and health related activities. Open-ended interviews will seek insight into beliefs and values concerning health, lifestyle, diet, obesity and diabetes, responsibility, health care and science. Researchers will triangulate results through interviews with significant members of respondents' health support system, including physicians, employers, case workers and family. The results will be published as a series of essays or short reports, each addressing a different aspect of health and health care, and as a book. Exploring the nexus of values, beliefs

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and behaviors, this project will add fundamentally to the understanding of health and health care in the United States.

"There was this pimple on my butt. I guess I shouldn't have popped it."

Nancy heaved herself onto the ER bed and rolled onto her back. "Excuse me. This gown don't cover anything." She pulled the blue gown down and a nurse twitched a sheet over her legs, but not before she had, indeed, revealed more than enough.

It looked as if Nancy had sat in scalding water: a stiff diaper of deep red skin wrapped her "private parts" from her buttocks to the deep crease under the bulge of her belly. Even as the nursing assistant began the routine of vital signs and signatures, I called for antibiotics and a surgeon. Even before we had taken her temperature, even before surgery and sepsis consumed her flesh, we knew that in all likelihood we were talking to a dead woman.

Gangrene of the genitals, also called Fournier's necrotizing fasciitis, is a rare infection of the deep structures of the skin. Bacteria dissolve fat and blood vessels and connective tissue, leaving wooden-feeling dermis dying over the decay. The only effective treatment includes debridement – the painstaking removal of every gram of infected tissue – antibiotics and intensive care. The patient comes out of anesthesia with a grisly void where there had been sex and sphincters – all gone, the focus of so much consciousness.

Not knowing this, precisely, Nancy's husband bent down to kiss her as she was wheeled down to surgery. They chuckled as a pack of cigarettes slipped out of his pocket. "Better get one quick," he said, offering her the pack, "They won't let you smoke in the operating room."

After they left, the nurse slapped the patient's chart. "I just can't understand someone who says they can't afford their medicine but they still buy cigarettes."

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The surgeon came down to the ER an hour after midnight and popped a can of Coke, his paper operating room mask still hanging around his neck. "We debrided 17 pounds," he said. "There was so much of it, we had to bring in a scale and weigh it."

Stories like this, of complications of diabetes, of obesity, of tobacco abuse, of the uninsured and the working poor pack the air waves as the Obama administration struggles with health care reform against a tide of well heeled lobbyists, advertising campaigns and popular opinion. Everyone agrees on one thing: American health care is expensive. How to deal with the cost is a question of political power and the influence of money – and of culture.

The need for affordable health care has never been greater: baby boomers and their parents are finding the limits of healthy longevity even as younger generations are shedding wellness to shoulder the burden of fat. It seems we have forgotten that health is a natural state, the default program for most beings with access to clean air, food, water, exercise and a wholesome means of making a living. We have normalized ill health, dysnutrition, an aversion to physical movement, surgical solutions, the swallowing of pills and a system of health care so expensive that an uninsured working person must devote the better part of a week to pay for a physical exam and the blood tests confirming the absence of high cholesterol, kidney disease and anemia. Add a mammogram or a prostate blood test and the cost pitches into next week.

As we have come to be increasingly dependent[1] on screening, pharmaceuticals and surgery, we have come to believe that health can only exist in the context of access to expensive products and services. Health is something we must buy. Health insurance is the key to this precious commodity. And health insurance is also very expensive.

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[11] University of Arizona anthropologist Mark Nichter describes tobacco as a "dependence industry affecting the world on multiple fronts ranging from the micro (cellular) to the macro (society, global relations)." (2003: 143-144). The growth strategies of the health care industry deserve further investigation along these lines.

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In the United States, we spend more per capita buying health and health care than do the people of any other nation, yet by any measure we are far from the healthiest of countries. The USA ranks 49th in the CIA's *World Fact Book on Life Expectancy at Birth*, nestled between two tiny Pacific islands and Albania. And, within the USA, incontrovertible disparities of health across the demographic spectrum are documented in public sources. Being poor or Black shortens life. Yet, being able to purchase more of the commodity health buys wealthy Americans just 4 more years of life than their poorer countrymen – and those additional years place their life expectancy still below that of the average citizen of a score of other nations, including those of Scandinavia, Macao, the Cayman Islands and tiny Andorra. Does some aspect of the commodification of health make even the wealthy less healthy?

Building on the work of Brown, Starr, Singer, Briggs, Brody[2] and other historians, social scientists, medical researchers and philosophers, this project explores the nexus of culture, science, profit and health in the 21st century. Over the course of two years and through a series of day-long to week-long visits, ethnographers will observe the daily lives of a dozen participants drawn from the spectrum of American demographics, accompany their subjects to health care appointments, participate in health-related activities, and pursue thoughtful discussions of health, illness, science, freedom, responsibility and the free market. The researchers will follow up with semi-structured interviews on the same topics with key members of their subjects' health support systems, including physicians, employers, caseworkers and family members. The grounded nature of this research will doubtless lead to some evolution in process; a closely-knit team of ethnographers, analysts and coders linked through social networking and face to face meetings will maximize the validity of the findings. Data comprised of artifacts, notes, and audio, photographic and audiovisual recordings will be entered into

[2] Not included in the citations because their books are foundational and widely available.

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AtlasTI and coded. The results will be published in a series of approximately a dozen essays, beginning some 3 years after the start of the study. The essays, in turn, will be brought together in a book under a summative analysis and conclusions.

The composite patient Nancy's life and demise is a scenario from which can be drawn key issues for in-depth study. A preliminary list of topics includes the following:

- Health and money
- Diet, exercise and obesity
- Infection and antibiotics
- Diabetes and its management
- Health care and health insurance
- Health literacy and self efficacy
- The cost and efficacy of medications and the pharmaceutical industry
- Science, progress and the future
- Death and the quality of life
- Entitlements, work and disability
- The industrialization of medical practice
- The relationship between patients and physicians or nurse practitioners

The prompts and probes for an interview about health and obesity might include the following questions: What is health? How do we find, recover or keep health? Whose responsibility is your health? Does this change if you are sick, poor, alone in the world? What is a good diet? Do you have access to the ingredients of a good diet? Who controls what you eat? How important is physical activity, and what is exercise? What is diabetes? Is it a serious

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condition, or normal? Why do doctors want you not to get fat? What does fat do to your body? Is it possible for ordinary people to lose weight? What do you think of weight loss surgery?

A "thick" analysis will reflect the research findings back into current sociology, anthropology and health sciences literature, inviting transdisciplinary discourse and adjustments to health policy.

This research shifts emphasis from reductionist generalizations to the layered particularities of individuals and contexts – from broad policy to the intimate level at which, in a free society, decisions are made. Primary values, except in the jingoistic application of election campaigns, rarely enter debate because they are so deep-seated that they are invisible until challenged or questioned. However, these underlying assumptions determine individual and population acceptance of behaviors, such as smoking, and conditions, such as obesity and diabetes, and whether and at what point interventions might be effective. By populating quantitative data with ethnographic detail, showing how Americans believe, think and live their choices, this research will contribute fundamentally to public health and policy in the 21st century.

Getting a grip on the escalating cost of health, on our current dependency on technology and pharmaceuticals, and on the overwhelming burden of ill health in the United States will require a transdisciplinary and multi-level approach that extends from the highest levels of government to the "cellular" level of individual belief and understanding. This research, beginning with the suffering of one patient in Northern Arizona, is an entry into the particular, a perspective that has been missing from the health policy discourse in the United States.

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Citation

Nichter, Mark. 2003. Smoking: What Does Culture Have to Do With It? *Addiction*. 98 (Suppl 1):139-145.

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