21A.216J Dilemmas in Bio-Medical Ethics 2005/5/9 (M), Week 14, Class 25

Reading: Paul Farmer. Pathologies of Power

Comments: Farmer was on James's dissertation committee and is one of the most visible physician-activist-anthropologist and his organization Partners in Health, once based in Central Square, now at Harvard MS, questions of pharmaceutical pricing, treatment of HIV/AIDS, and resource course settings. Programs in Haiti have been recognized as models for HIV/AIDS management in extremely poor countries. His style of writing does not mince his opinions and writes to mobilize his readership and has developed a following around him around the global that is spurring physicians to take on questions of social inequality. We've looked at clinicians staying within institutions whereas he is advocating something different. To what extent does a physician have a responsibility to address issues beyond the walls of the institution? Farmer is saying that issues of histories of repression, structures, economics, and gradients of inequalities in societies such that the poor are most often caught by affliction and diseases. His notion of structural violence—actually originated or proposed in 1960s, looking at social problems as acute rather than chronic (can discuss more later), and calling social inequalities as violence to describe generational issues of poverty and structural inequalities can be a form of violence that is equal to disaster or political violence. James disagrees uses of term "structural violence" for theoretical reasons but which we will not go into now. Please look over Farmer but also take a look at James's article.

Student Presentation

Author: Paul Farmer. HMS anthropologist, social medicine MD, Brigham and Women's Hospital, Partners In Health, a health and human rights organization. Winner of MacArthur genius award, Margaret Mead award.

Summary: He presents a lot of stories of life and death to elucidate ideas of health and human rights. Presents experiences of a lot of individuals. Tries to provoke our thinking—suffering of powerless people, human rights, economics.

Chapter 1. Pestilence and Restraint.

On Guantanamo and the logic of quarantine. Describes political situation when Aristide was ousted in Haiti and people fled for the US. People were arrested, and sent back to Haiti, after which they were executed. Political situation in Haiti was focus of the press.

Inmates in Guantanamo had issues of mistreatment and government tried to address the situation. Lawyers tried to protect policies by saying that Guantanamo is not

US and therefore US laws did not apply. "Our laws don't apply because it is not our soil." Leased since 1903 from Cuba and not under jurisdiction of Cuban law. Because Guantanamo is outside US territory but under US control. US government was trying to argue that US and constitutional laws don't apply to refugees there. Currently, in Guantanamo there are issues of abuses of detainees. These are individuals who are arguing that due process is not needed. Military corps is used also.

Similar arguments made to interdict when refugees are at sea and they are on their way to seeking asylum. When interdicted, they are outside of international waters and not under the purview of any particular nation's laws. Two spaces outside of law in social theory—spaces of exception, where strange things and subversion of law can become the norm. Keep in mind how spaces are used and defined to provide different treatment.

Also think about Nazi Germany—suspending rule of law to carry actions against people and has origins in that time period.

People with disease were treated with no rights at all, no lawyers present. No indication of their treatment: separation without treatment. The unavailability of treatment was caused because cultural differences. There was the prevailing notion that the cultural practices would lead to patients not accepting treatment. Is this a valid argument? How is culture being used as an excuse for mistreatment?

Use of forced contraceptives—women's health and violation of human rights and injected with various contraceptives. To control the population and to prevent AIDS from spreading. The language of humanitarianism to justify repressive actions—to allow their continued detention as a humanitarian gesture rather than send them back to Haiti in time of political upheaval. The humanitarian rhetoric can be used to do such things.

Affected presidential platform of new president and make it easier for Haitians to get into the USA; he received a lot of criticism. Camp interns went on hunger strikes and it was hard to get their voice out to the world and there was no media access to see what was really going on. The power issue—victims had no voice and those in power could discuss the situation.

Naval base sanatorium was a dungeon but misrepresented as something better.

Talks about Dr Pérez who changed sanatorium's conditions and better for those who needed it. It was better than Guantanamo but received a lot of criticism. Comparing Cuban vs. USA policies—there is a greater chance in the USA for abuse and racial discrimination.

US was not supportive of Cuba and put embargos, hard for Cuba to maintain health policies. To counteract US embargoes, they tried to keep their health standards.

Describes differences of Cuba and Haiti. Live and die rich in Cuba vs. in Haiti there is no such expectations or healthcare system.

Summarizes what is presently happening in Guantanamo and describes how that might also be happening in Afghanistan since there is no media or press there to cover the treatment.

James visited a detention center in Miami on a Human Rights Observer Mission in March after Aristide was kicked out for the second time. Individuals who flee communist countries were given preference; countries with dictators who were pro-US did not get as much preference.

After 2001, Haitians were depicted as threats to national security. Bush argued that because Haiti was so volatile, it could be a ground for terrorists.

Paul Farmer—the suggestion that despite the fact that Cuba is not democratic it is doing a better job than a democracy. How do those in the US government view Paul Farmer's work?

Chapter 2. A plague on all our houses.

On tuberculosis. Penitentiary system and worsening conditions, loss of supplies, and increasing difficulty in treating patients. There is a tendency to blame TB services rather that social and economic conditions that are to blame for their failure (Farmer's argument). Difficult to follow what they want to do for treatment.

Humanitarian organizations were trying to get a confession that prison conditions were deplorable. Farmer: people already agreed that economic conditions are not up to mark; rather, humanitarian organizations should try to promote economic solidarity.

A shift of Farmer to side with government—as PIH becomes increasingly institutionalized.

Farmer's proposition to use first line vs. second line drugs was rejected because it was not cost-effective. More concerned with financial aspect rather than what would be really beneficial.

Directly observed therapy short course (DOTS)—whether people are actually taking their medicines and how to prevent TB from developing into MDR-TB. To watch and make sure that people take their medicine, twice a day.

People argued that this is a new form of bio-politics and surveillance, even if it is to eradicate the disease and to cure. Question: is it ethical to force treatment if it will benefit greater good of society?

- Need to be vaccinated before going to school
- Difference between DOTS and Cuban institutional screening:
 - o clearly patients must be consistent with their medicine
 - o to what extent do people consent to receive anti-depressants along with TB meds
- to intervene at the level of mood for sick patients, it seems controversial
- culturally, there is a tradition of taking various remedies for sickness; people will want injection or pill. is this exploitation? the drug could increase appetite.

Who should decide what course of action to take—infectious disease as a threat to the entire world—who will or should be involved? Private foundations should fund treatment. A global problem of who should be involved in resource rich countries.

 Farmer makes an argument that disease does not have orders and that disease is everyone's responsibility and where do you draw the line on responsibilities.

Standardizing treatment in Russia is difficult. We need to attack pharmaceutical companies to bring their prices down.

- Necessity for drug companies to recover cost of research and development of drugs
- How do people attack or create drugs? It is strategic but nevertheless very expensive.
- Making the drug and various levels of development—clinical testing
- \$800 million dollars take into account failed drugs.
- Request: keep in touch if you are going to work with Big Pharma

Questions:

- MDR-TB appeared in New York and massive programs were given expensive treatment. Cost effectiveness of the program—still seen as good for the entire public even though it was very expensive.
- Situation in Russia was much worse than in New York; but the course of action was vastly different.
- Countries that lack resources to provide for its citizens—what do you do and who should take the place of the state? Please read the Haiti political economy of trauma article.

(continuation)

- "Life or greed"
- Treatment has arsenic and can have serious side effects.
- Destroys vessels, side effects; drug does not guarantee recovery
- Patients feel worse
- Pharma company drops the case and provide more affordable drugs while government agrees to respect World Trade regulations.
- How will these drugs really become available?
- How effective are these drugs?

It's My Life. 2001. http://www.dayzero.co.za/steps/films/films_52/itsmylife.htm ARVs allow people with AIDS to live longer. ARVs fail to be provided to hospitals. President questions link between HIV and AIDS. Film by Brian Tilley.

- Quality of life is reduced
- Investment in arms and scrap metal vs. AIDS patients
- world's largest pharma companies vs. S. African government to provide affordable anti-HIV drugs
- commercial interests vs. life of people?
- March 2001 through Pretoria to purchase generic drugs
- treatment action campaign as a friend to the high court
- how to ensure that their (TAC) voices are heard
- To profiteer from people's lives—live or greed—anything else?

• Activist Zackie Achmat will not take ARVs because not everyone can have access to them

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