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Prescriptions & Palliations:

Obscure(d) Meanings, Strategic Reflections, and Illuminating Subtexts

by

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Introduction

My aim in this paper is to illustrate the potential dangers of categorizing and labeling in medicine. When we apply labels to patients and to each other, we make it easy to fall upon stereotypes brought to mind by those labels. I will explore the implications of categorizing and labeling in three settings: in doctor-patient interactions, in AIDS outreach, and in medical education. In the first case, I will use experiences from my first year of medical school to expose the limitations of the way we describe our patients to each other. In the second case, I will show what can happen when we apply these labels (in the words of Henrik Blum, "We form an opinion about a patient based on a few key words in someone's description of them, and what stereotypes we have about those labels. But how can you presume to help someone when you don't have any idea who the hell they are?"), and present an alternative model for learning how to help the people we work with. In the third case, I will use classroom experiences to explore the process of conscious and unconscious othering that takes place in medical education.

I. Diary of a First Year Medical Student

Medical Interviewing Class #1

We are discussing a section of the medical interview and write-up: the patient's "identifying data". Our textbook, "The Database," informs us,

Always include:

- 1. Name
- 2. Age
- 3. Race (and primary language if other than English)
- 4. Sex
- 5. Informant and assessment of reliability

(Some clinicians find it helpful to include here such defining characteristics of the patient as major diagnoses (e.g. Down's Syndrome or AIDS), or health risks (e.g. homelessness or smoking). This *may*, however, *introduce bias* into the remainder of the history.)

I feel too tired to contemplate the equating of homelessness and smoking, or the typically absurd notion that, barring inclusion of a diagnosis or health risk, the history has a chance of being bias-free. Instead, I muster the energy to broach the "race issue" with my classmates. (It has, after all, been several weeks since the last time I tried, and maybe I can get in a few more ideas before the shifting in seats and eye-rolling signal the limits of their tolerance.) I explain that I am uncomfortable with the use of "race" as an identifying category, because "race" can mean many different things, is not a biological category, and will likely be used in the service of racism, consciously or not. I ask that people ask themselves why they want to include it, whether is has any relevance to the patient history, and if they decide it does, that they not try to determine a person's race without asking the person how they identify. Doctor, our instructor, pipes in with the obligatory genetic determinism blood disease excuse.

"Many diseases, such as sickle cell and thalassemia, are most prevalent in certain races, so it's important to include race so as not to miss a diagnosis." My classmates nod in agreement.

Deciding that no one wants to hear about the social construction both of race and of epidemiological correlations again (I gave that speech last semester), I continue that the inclusion of "assessment of reliability" is problematic, especially when placed adjacent to "race," and I ask people to at least consider why they might assess a patient to be unreliable, and to write the reasons down. It would be too easy to let our biases run free and unchecked, otherwise, and to decide that all our racially identified blood disease risks are also not reliable sources of information about their own lives. Maybe if we write something down, I tell the roomful of blank stares, we will hold ourselves to some degree accountable for such judgments.

"Absolutely," chimes in Doctor. "If your patient has dementia, or some other mental disorder, then you should put that down in the assessment of reliability." My classmates take notes on this last bit of advice.

"Susan," Doctor says to me, softly and condescendingly, as if to a hurt child, "all of us are uncomfortable with parts of our role as doctor. I, for example, am sometimes uncomfortable taking a sexual history. You are uncomfortable talking about race. That's fine, but try to work on it. It will get easier with practice."

Human Growth and Development

A professor from the School of Public Health gives us three lectures on physical growth and development. He spends the first lecture explaining the difficulty in determining whether a short person is "a very tall dwarf, or a very short normal person." He talks about the importance of measuring height to monitor "normal" development, and shows a chart of average heights of boys at different ages, from several countries. All of the average heights in Asian countries fall below the line marked "normal." He comments that a model of a fetal vascular system, made by injecting plastic resin into the blood vessels, "looks like Oriental art, doesn't it?"

At the beginning of this professor's next lecture, I offer some comments to the class, and give the same ideas in written form to the course instructors, who had not been present at the previous class. None of my classmates say anything to me in response, and the professor looks puzzled and goes on with his lecture. Here is what I wrote:

We just had lectures on growth by Dr. __. He showed endless slides of growth charts and opened the lecture with charts of heights of "normal" children and dwarfs. I found the premise and assumptions of his presentation offensive in the extreme. He and his slides bandied about the words "normal" and "abnormal" without the slightest thought to the power and meaning they contain. Physical "differences", deviations from average or "normal", have been used throughout history to justify racism. There is enormous power in being able to define normal and abnormal or pathological, and I hated having these ideas presented to us without a larger context. The standards of "normal" physical characteristics- height, weight, appearance- are arbitrary standards, socially constructed. We are surrounded by media images of physical ideals, and simultaneously with starving and bulimic teenagers, with women voluntarily subjecting themselves to surgery for breast implants and liposuction, with whole races of people made to feel inadequate because of their physical differences, because they fall too far off the curve of "normal" and desirable European physical characteristics. I brought up my complaints during his lecture, but I felt that they were met with a complete lack of comprehension. Dr. __ did make an attempt to define "normal," as "without demonstrable disease". Of course, this brings up the next and closely related issue of defining disease. He seemed to imply that short stature, because it could in some cases be treated with exogenous human growth hormone, was a disease: if we can cure it, it is a disease. I find this extremely problematic, given that people of different races vary so greatly in average height. I think that such standards are problematic and potentially dangerous, and that we should be very clear about our terms, their meanings, their potential uses/misuses, and their limitations. We should also pay close attention to who has the power to define the terms and to impose labels, and to what happens, and to whom, as a result.

My reactions to Dr. __'s lectures have much to do with my identity as a Chinese lesbian who was considered to be short and fat as a child. In each of these categories I have been labeled as different, abnormal, or pathological. It has only been in the last few

years that I have developed the confidence, knowledge and self-esteem to see myself otherwise.

Our instructor's reply:

Susan.

Parents, teachers, and other children (doctors too) do have a way of helping us define ourselves as children (like 'short' or 'fat') which as adults is amazing to imagine- we do grow up and change. What's important to keep in mind is the force that allows you as an adult to develop 'confidence, knowledge and self esteem' to define yourself and which escapes others.

I am stunned that she chooses not to address any of my critiques, but focuses only on my personal revelations (which I now regret having included).

She is saying, I think, that she can't imagine that I was seen as short and fat, given the way she sees me now (Tall and thin? What about the Chinese lesbian part?). Or, she could, in that first clause, mean that it's "amazing to imagine" the insensitivity or cruelty inherent in applying those labels to children. I doubt that this second interpretation is applicable, however, because she speaks not of labeling, but of "helping us define ourselves." Here is the specter of autonomy- we each define ourselves; outside forces simply help us in that task. Whatever her implication in that first clause, when she continues, "we do grow and change," she brushes aside the normalizing role and lasting impact of labels, in effect excusing parents, teachers, children, (and parenthetical doctors), for applying them. She suggests, it seems to me, that those early characterizations become meaningless if and when we either get taller and slim down, or gain the maturity not to let those labels bother us. Thus, each of us, through dieting and self-actualization, has the potential to overcome the burden of normalization.

Fortunately, I am rescued from my confusion with her vague, noncommittal language, when she, in her second sentence, tells me "what's important to keep in mind." The key, it seems, is that I was able to overcome external forces and blossom into my new thin, autonomous self, whereas that ability "escapes others." I remember a scene from ten years ago, when I was staying with some migrant farm workers in the Central

Valley. Looming over the dilapidated shacks that were supposed to house the workers, was a huge marquee mounted on the roof of a church; it proclaimed, "Capitalism guarantees opportunity, not success." I suppose our instructor would say the same thing about social and medical normalization.

Thesis Seminar

The medical students pursuing theses in "Health Policy" (the other choices are behavioral science, medical ethics/humanities, and physical sciences) meet every two weeks to present their work and ideas. I present the following:

Many of us are engaged in political projects; by this I mean critically analyzing aspects of medicine/health care delivery, in order to understand its workings, implications, problems and limitations, and to suggest strategies for change. At every level of medicine, from the individual to the institutional, and at each site of action within these, the spoken and unspoken rules that govern the workings of medicine, and thus govern the people interacting with it, are rearticulated, reworked, and reinforced. One can thus pursue such a political project at endless sites and levels-policies, laws, patients, providers, practice guidelines, attitudes, practices, etc. Often we focus on large external enemies and forces, blaming them for the inequities in medicine. I want to look at my own practices, and those of people with similar political goals, to make visible the invisible practices through which we may unknowingly reproduce that which we want to eradicate. I want to meticulously unravel the finely woven threads where oppressions, transgressions, insults, violence occur in medical interactions. I want to do this not by policing the actions of others and myself, and not simply by pointing out our mistakes, but rather in the spirit of building something new, collaboratively. I want to talk to other political health care activists, and not as an objective outsider or observer, for there can be no such thing. I want to make explicit my goals, perspectives, and to work with others to explore ways to rework our practices and strategies and ways of understanding. I want to explore the concepts of "strategic essentialism", "contingent foundations" and "conditional transgressions." How much difference does it make to understand things in context, and does it mean we act differently once we contextualize? How constrained are we, really? As much as we imagine? Throughout my thinking about these issues, the limitations of categorizations, I kept returning to the impossibility of understanding or working with people without categorizations. But at what point do imagined constraints become excuses? How can we push things further? In The Woman in the Body, Emily Martin says, "Although I will be critical of many central ideas current in medicine because I think they are demeaning to women, doctors as individuals are certainly not to be held responsible. Medical culture has a powerful system of socialization which exacts conformity as the price of participation (p. 13)." I want to challenge this assertion, because I think medical culture does not simply exists outside of us; rather, we participate in reproducing it every time we act as medical students, doctors. And in so doing, have constant opportunities for subverting this medical culture. I see a great danger in this imagined overconstrainedness, in that we can use it to absolve ourselves of responsibility for throwing our sabots in the machines, or of producing something else.

At the end of my talk, I say that I am trying to figure out how to incorporate these ideas into a thesis project, and ask for questions, comments, and suggestions.

"During your talk, the phrase that kept coming to mind was 'patient-centered.'

Don't you think you should talk to patients to find out what *they* want?"

I explain that I think there's a danger in always focusing on the patient, because it assumes that once we are told what "they" (medical students and doctors tend to forget that they too will at times be patients) want, we will understand and be able to deliver. But, more often than not, we don't deliver. I want instead to examine the assumptions we make about patients, and how those assumptions shape and are shaped by our practices, how they impinge upon our ability to deliver.

"Susan do you keep a diary? Maybe you could record your feelings as you go through medical school, and how your feelings about patients and about yourself change over time."

I respond that I do not intend to make this a personal account like a diary. Rather, I want to critically examine practices and assumptions we take for granted as necessary and harmless.

"Susan, you can't simply record your opinions about things and call it a thesis," warns our thesis faculty advisor. "You need to come up with an academic research project. This entails some original thought, and writing from an objective position."

Not willing to engage him about the academic legitimacy of critical theory, I reply, "There's no such thing as objectivity."

"Well, we do all have biases, but you need to put those aside as best you can."

We continue this non-debate until I am so frustrated that I thank him for his advice and call on someone else.

"I think he has a point, Susan. It's so easy just to criticize things. I think you have to look at why things are the way they are-- because it works. Maybe the medical interview as we learn it is the best way to get information from a patient. Why don't you take a look at that?"

I talk again about the danger of our imagined overconstrainedness, but by now I feel, as I often do when I speak in class, that I am no longer making sense, that I am just repeating myself, and that no one here will understand. I think they perceive me to be

saying "those things" again, and are tiring of it. I forget what my point was in the first place. Too tired to do anything else, I join the side that's winning, and dismiss my entire project.

After the meeting, Heidi, a second-year student and one of my precious few allies and soul sisters in medical school, whispers to me, "It doesn't matter what he thinks. All you have to do is find a three faculty members for your committee who will sign your thesis, and you can do what you want." I am beginning to understand why she participates in only every fourth or fifth classroom debate. I need to start conserving energy, and choosing my battles more strategically.

Medical Interviewing Class #2

A classmate asks for suggestions on how best to ask patients about their identity.

"I've asked patients how they identify ethnically, but they don't seem to know what I mean."

"A lot of people don't think about having an ethnic identity, so maybe that's why they look confused."

Or maybe, I counter, they feel, as I do, that it's irrelevant to a medical interview. I've said this before, but I really wonder why we need to include "race" as an identifying category for our patients. It doesn't seem to add any useful medical information to the chart. My classmates take turns misconstruing what I have said.

"I don't care whether you ask about race, or whether you write it down or not, I care about your attitudes about race."

"By not writing it down, you're just avoiding the problem. I think its important to think of a solution."

"A person who is racist will treat a black person badly, whether it is written on their chart or not. As soon as they see the patient, they will see that they are black."

"I think we're all assuming that you can tell a person's race by looking at them, and that isn't always the case."

"Besides, I don't think it's always an insult to use a person's race. Lots of people are proud of their races."

Angry and frustrated at having been so completely misunderstood, I repeat myself: I want us to think about whether "race" is an appropriate identifying category for a medical chart, and I want us to think about how writing it down shapes our thinking about the patient. That doesn't mean that race will disappear if we don't write it down. It doesn't mean that people won't find other ways of "race-ing" their patients. Of course race is very important in people's lives-- I am not claiming otherwise, and I have included

in my write-ups all information a patient considers important to their social history, including "race". I am talking distinctly about writing down a person's "race" in their identifying data-- I don't expect that by not writing it down, people will no longer be racist, of course not. But everything we do, everything we say to a patient, everything we write down on a patient's chart, every way we categorize a patient, is shaped by and shapes our thinking about our patients, and that's what I'm trying to address.

"Well," says Doctor, "that's the perfect segue into your story, Bianca."

"I have a brief story which I believe might illustrate the importance this issue can assume in actual clinical situations. The situation I will describe took place when I was shadowing my preceptor as he visited several of his patients. Well, to put it mildly, my preceptor is not the most pleasant or sensitive of individuals. As we were about to enter a patient's room, he glanced briefly over her chart. She was a 19-year-old African-American woman with a bump on her head from a car accident. I noticed a very subtle change come over him. He entered the room brusquely, and without ever going over to the patient, he fired questions at her from across the room in an extremely confrontational manner. Of course, I felt terribly uncomfortable and embarrassed, and made eye contact with the woman several times. I could tell that she was looking to me for understanding. Well, finally, she asked him if he could just look at her head, but he said 'no', that a neurologist would have to do that. I felt that she was appealing to me for understanding, so I went over to her, hoping just to provide some comfort. I touched her head and told her that sometimes these things take a while to heal and that she would probably be okay. When we left her room, my preceptor reprimanded me for doing what I did, telling me that it was inappropriate, and that she was the type of patient who was just 'looking to sue.'"

"But, Bianca, how do you know that it was because he saw her race written down that he acted that way?"

"I could just tell. Call it intuition, a hunch. Certainly, it was subtle, but it was very clear to me. I would suggest that it was because he looked at her chart and saw her race that he positioned her as cultural other and assumed such a hostile attitude."

"So what do you think, class?" asks the rejuvenated Doctor.

"Well, I think Bianca handled the situation really well."

"Yeah, what you did was really great-- that you were able to reassure the patient without overtly rebelling against your superior. You didn't just call him an asshole in front of a patient. You found a clever strategy to show him, by example, that there was a better way to treat the patient."

"It was brave of you to do what you did in front of your preceptor."

"I think that was an effective way to handle the situation, one that we can all learn from."

I expect the room to break into a round of self-congratulatory applause.

This discussion began as a question of whether and/or when "race" can serve as a useful piece of data in written patient histories, and of how the inclusion thereof can serve to reproduce racism and stereotyping in medicine. It has now been transformed into an unseeing example of itself. My concerns are swept away in the wave of admiration that flows through the room for the patronizing appropriation by Bianca of the authentic abjection of her anecdotal sick black woman. In my insistence that the question is one of broader political concern, rather than simply one of my personal concern, I am unintelligible. In dealing "effectively" with race, not in an angry personal way, but in a calm professional manner, Bianca is legitimated as the political actor, the good progressive doctor-to-be. Rather than addressing the structural embeddedness of racism in medicine, she uses it as a stepping stone, coopting the symbolic oppressed. She preserves the latitude already afforded those who are ensconced in the status quo. She provides us with a way at once to elevate ourselves and to keep others in their abject

dependence, thus making our reaching down "to help" so much grander a gesture. She is held up as exemplary.

Subversion and the Inner Child

My classmates have compiled a report from the national medical student conference they have just attended. Among the reports is "Bernie Siegal: Love, Medicine, and Inspiration." I remember Bernie for having provided many a friend with AIDS with reason to blame themselves for their disease, and, because they were not able to sort out "why they needed their disease", for not "allowing" themselves to heal. How appropriate it is that he had been invited to speak at a medical student's conference. Here is an excerpt from the report:

He also offered suggestions for subverting the power dynamic in medical institutions, and restoring control to patients as well as others (nurses, students, interns) on the low end of the hierarchy. He spoke about a young cancer patient who was given a water pistol, with which he threatened anyone who approached with the intention of giving an injection, taking blood or performing some other unpleasant procedure. The boy would not permit the staff to touch him until they drew a picture of themselves, to his satisfaction. In this way, he was able to retain a sense of control over his body and his life. Siegal suggested that, along with their beeper, all medical students ought to be similarly issued a water gun on hitting the wards!

In this setting, then, such an insipid suggestion is taken as a method "for subverting the power dynamic in medical institutions", whereas any substantial critique of power dynamics, anything that would require us to change our behaviors, is shut down.

Class Meeting

Every six months or so the twelve of us get together for a class meeting. We talk about concerns we have with the program, classes, interpersonal dynamics, and whatever else comes up. Tonight is our first meeting since October. I've been thinking for quite some time about how to share the feelings I have of being silenced regularly, how to ask people what they think when I bring up "race" yet again in class.

After several bureaucratic matters are broadcast and discussed, one student admonishes us to refrain from "getting personal" in our instructor evaluations.

"Some people wrote some really mean things last semester, and one of our teachers really had her feelings hurt. I talked to her, and, I mean, she really felt bad."

I was one of two or three people who turned in critical evaluations of her course, and I feel him speaking to me.

"Yeah," adds another student, "I couldn't believe how harsh some of the stuff people wrote was. Like about our development teacher."

Again, I feel him speaking to me, for I was critical of her class as well.

Other voices are layered upon these, most issuing appeals for "diplomacy", "being nice", and for "not being disruptive".

In the hallways between classes last semester, my classmates frequently made specific and "harsh" complaints about our courses and instructors. The first student passed a note to me during one of our lectures. On it he had drawn a picture of twelve rats in a cage. After class, he pulled me aside and said that our teacher was "as domineering as a steam roller. I get the creepiest feeling just being in the same room with her. I hate the way she treats us like lab rats—she really shouldn't be teaching." The second student often complained to me about the unrelenting psychoanalytic content of the course that was supposed to teach us about entering the world of the patient, their lives, and how they are impacted upon by their illnesses. "This lecture was supposed to

be about the patient as person, and she just talks about transference. It's ridiculous." After the semester, I read the anonymous evaluations for all of our fall courses, and was astounded at how banal and uncritical most of them were: "this course was pretty good...", "she's really nice...", "it might have been nice to learn about other theories in addition to psychoanalytic ones...", etc. The most frightening one for me, though, was "I enjoyed watching our teacher handle certain difficult students in the class." This is the single medium of protest, the sole semblance of political voice recognized as legitimate in our program. We are allowed to speak in anonymity, without fear of reprisal for our honesty: because the number of students is so small, an administrative assistant types our comments onto another sheet so that no one's handwriting will be recognized. All of our instructors make an effort to explain this process to us, and to encourage us to be forthright in our assessments. All of the evaluations for the medical school program are available to students. I had already been angry that my classmates had not made their complaints in their evaluations, and that one had even positioned him/herself apart from the 'difficult' ones, which surely includes me. They, meanwhile, find my critique of our classes exceptionable.

Struggling not to show my frustration, I answer the charges. "I feel that you're speaking to me, for I wrote some pretty strong evaluations. But I don't think they were personal at all. The things I discussed, I felt, were pertinent to their suitability to teach courses in this program. I feel that what I wrote was constructive, and I also think that disruption is often essential to effecting change. These terms are so subjective-- 'nice', 'constructive', 'disruptive', 'diplomatic'. No one can decide what those mean to anyone else, or take responsibility for anyone else's evaluation. I have used, and will continue to use, the course evaluations as I see fit."

"Well, it does reflect badly on the class as a whole. I think we should focus on constructive comments, not destructive or disruptive ones."

"And disruption is okay when used in moderation. But when you disrupt all the time, you really lose your effectiveness."

"The problem is, since the evaluations are anonymous, a teacher who gets a bad evaluation could think that any of us had written it. I mean, we have to work with these people again."

To my shock and dismay, several people agreed with this. Let me see if I understand, I think to myself--"I kiss butt, and I don't want it ever to appear that there was a possibility that for one moment I was *not* kissing butt" -- could that really be it? The anonymity in this anonymous forum creates fear in my classmates. They are afraid of being erroneously attributed responsibility for a negative comment. People who have been complaining about certain courses and instructors all semester have gone to the teachers who received "negative" or "harsh" evaluations to let them know that they were not the ones who had written the nasty things. They see the way I get treated by professors, though, in return for my "disruptions." I don't blame them for being afraid.

Exhausted after the class meeting, wondering whether I have the energy to keep fighting, I answer a phone call from my classmate Neva.

"I just came across a quote I took from Joycelyn Elders at the conference last week, and it reminded me of you. She said, 'one person with courage is a majority.' I just wanted to tell you that." For the first time in weeks, I feel hopeful.

Hospital

I interview Mr. C., a man who has a stomach tumor. He is waiting for the results of the biopsy later that day, he tells me, but is hoping for the best. Later in the interview, when I ask him about any family history of cancer, Mr. C. tells me that his father and two of his three siblings died of stomach cancer. Oh no, I think, unaware that my face is betraying my thoughts and sadness, this man has stomach cancer.

"I guess that doesn't bode well for me, does it?"

Horrified, I realize that my facial expression has just been read as medical opinion.

Policy Papers

Spending more time than I want trying to understand my classmates, I stare at the twelve bundles stacked on my desk: our final projects from our Health Policy course. In these papers many of us make our first explorations into our thesis projects, and in them I hope to find hints to the way people envision themselves, the way they position themselves within the medical world, in relation to each other, to the 'medical establishments' and institutions, and to 'patients'. Perhaps with some understanding of these, I can begin to make sense of the dynamics of our class interactions, of how we are shaping each other, of how we reproduce and reinscribe the biomedical status quo.

I am first struck by the groups chosen for 'study': homeless people, homeless women and children, poor mothers, poor families, Southeast Asian immigrants, Mexican immigrants, transgendered sex workers, battered women, psychiatric Medical patients. Most of us have chosen groups with whom we do not identify; many of the groups are presented as helpless, and thus in need of our help. I try to distinguish myself from what I perceive as the "save the whales" mentality of rescuing the "helpless other", a mentality that drives many of these projects, by rereading the discussion of my project on transgendered sex workers as a critique of the "reductionistic bias" in biomedicine and social service delivery. I find myself judging each project according to my simplistic schema of what is correct or not. I divide the papers into groups, according to whether the writer identifies with those about whom they are writing, or with the medical heroes. I wonder why it matters to me whether or not people identify with the groups they are studying, especially since everyone seems to have taken a patronizing and paternalistic stance towards the groups they studied, regardless of whether they so identified. I find it curious that the one African American student in our class wrote her paper on health food stores; I admit to wanting my world to be organized along neat racial and political lines, and that it simply isn't so.

I read through the papers and am shocked, though I wonder why, at what I find. Bianca has written about the virtues of government nurses giving home visits to poor mothers. She has interviewed nurses who provide this service in Oakland. By the fourth page of her paper, she has linked poor mothers to "household emotional problems, substance abuse, acute infectious diseases, HIV, and noncompliance." She lets us know that "individuals can be referred to Public Health Nursing by *any* professional or lay person." She explains that "the following are typical components of home visits: family planning, infant care education, assistance with/encouragement of breast feeding, education about maternal health behaviors, involving family members and friends in education, and information about health and human services." She tells us that the power to decide the timing and duration of the visits lies solely with the nurses: "Nurses know their clients well and know when to close a case." I am repulsed and amazed that she has already invoked some of the crudest stereotypes I know of, but I force myself to keep reading.

I present in its entirety her section titled "Cultural and other issues": "Translators are available and often assist in home visits. They would like to visit more low-risk mothers (as opposed to high-risk), but financial constraints preclude this."

Bianca proposes the following as possible outcomes of home visits: "Fewer incidents of child abuse would be hypothesized to result from the emphasis on education about infant care giving during home visits." "Increase in maternal employment is a consequence of the increase in maternal self-esteem fostered by the relationship with a nurse." Also mentioned are "fewer emergency room visits for young child injuries, fewer subsequent pregnancies, and a decrease in use of government services (e.g., AFDC)."

In conclusion, Bianca advocates building up the medical arm of the state panopticon. She recommends that the county create a "computerized high-risk client database, to which many referring sources, such as hospitals, perinatal projects, and physicians, would contribute." She also recommends that the county provide home

visitation "for a full two years after birth", in order to diminish the "hiatus in social oversight for children between ages one and four".

Disgusted with Bianca's right wing program, I turn to the other papers. There are others which I find equally appalling, but the tension of trying to piece together why they are the way they are overwhelms me. I had hoped to tease out some of the finely woven, imperceptible and insidious threads that run through the process of medical education, drawing us into the seemingly intractable edifice of power that is medicine. But the blatant ignorance I encounter unnerves me—it seems impractical to search for the finely woven threads when I feel like I have just been socked in the stomach and am going to vomit.

Reflecting on my reading of Bianca's project in particular, I remind myself that, though her "program" may sound "right wing", she presents herself and is accepted by many as an authority on feminism, and as an insightful, sensitive, and caring champion of the oppressed. All students in the Berkeley Joint Medical Program, it seems, see themselves as such. In this arena, where such students are valorized as the legitimate progressives, and where I am dismissed as the raving, angry disrupter, I do not know how to act.

Chair #1

At the end of each semester, each student meets with the chairman of our medical school to discuss progress and concerns. When I am asked if I have any issues, I tell him that I see meaningful discussions being shut down by students and instructors alike. Feeling cautious that day, I remind myself to speak in general terms, so as not to be misread as lodging a personal complaint. It seems, I tell him, that we are only allowed to congratulate ourselves for being good people, but that any critique of our actions as medical providers tends to be dismissed.

"Susan, do you think it's the content of what you're saying or the tone in which you say it that people object to?"

Though taken aback that he has assumed that I am the one being silenced, I answer that it's the content, of course. I never raise my voice or speak in anything but calm and civil tones.

"Well, that's not what your classmates tell me."

I am stunned. Only a week ago, at our class meeting, I had asked my classmates how they felt about my bringing up issues about race in class. One person replied, "I like that you bring things up. We can learn from overtone's opinions." Well, I continued, if anyone does have a problem with it, please let me know. I'm open to discussing it, and I certainly don't want to say things people don't want to hear, or that people think shouldn't be discussed during class time. I got no further response.

Now, I learn that some people indeed took offense to my contributions. Rather than speaking to me about them, though, despite my offer to stop bringing these issues up in class, some of my classmates have instead gone to the director of our program to complain about me.

"Susan," the director continued, "whenever you tell people things that challenge the way they think and live their lives, they're going to have a problem with your tone.

Now, you can continue to voice your beliefs in class, and continue to have people complain about your tone of voice. But it seems clear that your classmates aren't going to change their views because of what you say, so think about whether this is where you want to spend your energy. Another approach would be to change your tone, but I don't recommend that for you- it doesn't seem like your style. What you might consider is to keep quiet for a while, understanding that these people aren't ready to listen to you, and get your MD. We all have to choose our battles. When you get out, you can find places where your voice will be welcome and heard and will make a difference in the way people think. But it isn't going to happen here, not anytime soon."

I gather my belongings and walk away. For the next year, I abstain from political discussions in the classroom.

II. Steven

I met Steven in the summer of 1980, when we were both 16-years-old high school students at Harvard Summer School. He was one of the smartest people I'd met, sophisticated, from New York City, at 16 taking graduate courses in astrophysics. We became close friends that summer. A few years later, Steven invited me to stay with him for a summer in New York City. At that time, we were just starting to learn about AIDS. I recall at the time knowing that it was most common among gay men, and that we were all supposed to use condoms to prevent its spread. I remember talking to Steven about this, and that his response was dismissive and annoyed. He told me that I didn't understand- "You have no idea what this means." We were never able to get beyond anger in our conversations about AIDS. Later he became infected, it was frustrating for me at the time and ever since, feeling that I should have tried harder or done more to get him to use condoms. Over time I have come to have a better understanding of what happened between us back then. It isn't effective simply to tell someone to change their behavior, especially without understanding the context and motivations of that behavior. The motivation must come from within. Of course Steven didn't listen to me when I told him to use condoms. He was right- I didn't understand. Now, in an effort to understand, I have been spending a lot of time talking to Steven, hearing his stories, and learning from him.

"I remember when I was 7 or 8 years old, watching "The Getaway", with Steve McQueen and Ali McGraw, on TV. There was a scene with the two of them in bed, he holding her in his arms. I knew I was supposed to want to be Steve McQueen, holding beautiful Ali McGraw in my arms. But I wanted to be Ali McGraw, being held in Steve McQueen's arms. That was my first conscious dealing with my sexuality."

"I wanted to find pictures of naked men. I went to buy a Playgirl; I told the store owner that I was buying it as a birthday present for my mom- I even asked him to gift

wrap it. I did that a couple of times, but I knew that I couldn't keep using that excuse. For a while I stole Playgirls from stores. My older brother also had straight porn magazines, which had occasional pictures of men with the women, and I'd find those pictures and look at the naked men."

"My father used to bring home the New York Post. I would see ads in the newspaper for XXX movies, usually with a naked woman. But one day I noticed an ad for an all male XXX movie. It featured a bare-chested man- Jack Wrangler. He was wearing jeans, and them name of the movie was Gemini. It made such an impact- I remember the ad so clearly, as if I had just seen it for the first time yesterday. How fabulous, I thought, to have an XXX movie with all men! We lived in Queens, and my father worked in Manhattan. I knew that the same bus I took to my junior high school would take me to the train station, and from there I knew how to take the train to my father's office in Manhattan. So one morning, on the way to school, I stayed on the bus until I got to the train station. I took the train to Manhattan, went past my father's stop, and went to the movie theater. First I sat in the middle of the theater, then I moved to the front row to be closer. A man, in his 30's or 40's, came up to me and said, 'Do you want a B.J.?' I knew what he was talking about, and I said, 'Sure'. We went behind the movie screen. They had some couches, and he blew me. He asked me about anal sex, and I said, 'I don't do that', and I walked away. That was my first homosexual act. I mean, in camp I had played with other boys, but this was the first time I couldn't put it off to being a child. I made the decision to put myself in a sexual position with a man, not another boy. I was 12 years old. I'm sorry that I have no recollection of who my first was. I'm glad that we now have places for gay youth to go, but there was nowhere for me to go, no one for me to talk to, not at that age, at that time."

"After that I felt exhilarated. I kept going back, every few months. By my 2nd or 3rd visit, I went with this guy to the bathrooms. I told him 'I don't give head'. He gave me head for awhile, and then I realized that if this was what I wanted, I had to start

reciprocating. That was the first time I gave oral sex, and I chose to do it. That's why I'm so open about my sexuality now, because I was allowed to come to terms with it at my own pace, on my own terms. I wasn't ever forced, as some were. I always chose what to do and when to do it.

It is remarkable to me that Steven cherishes what choice he had, the control he exerted over his situation, that he sees this anonymous sex with older strangers in the back of a porn movie theater when he was 12 years old as sex 'on his own terms'.

"In the 9th grade, there was a boy I cared about. I would have loved for him to be my boyfriend, but I wasn't allowed to have that kind of relationship at that age."

What cultural forces were at work, that Steven knew that he wasn't supposed to reveal his affection for a classmate, but, in the logic of his 12-year-old mind, it was okay for him to travel alone to Manhattan and have sex with 40-year-old strangers in a dark theater? And what can this tell us about the normalizing power of our cultures, how we learn what is acceptable and what is not? What can medical providers learn from AIDS outreach methods and its failures, about trying to get people to change their behaviors?

To look for a different model, to look for ways of communicating and interacting that are not about authority figures telling people to change, I pursued an internship with the Asian AIDS Project. My work with AAP has been enlightening because I've seen that it is possible to work with and help people without positioning oneself as a hero in society, without reinscribing the abject subaltern position of those we help, without using them to elevate our own positions.

III. Decentering AIDS Prevention Efforts: A Study of the Asian AIDS Project

Introduction

From the beginning of the AIDS epidemic, people with AIDS have been described and understood, by the medical and public health establishments, as well as the public at large, to be gay men, drug users, and "innocent" people who received tainted blood through transfusions in clean white hospitals. As our scientific understanding of the disease has evolved, so too have the ways in which people with AIDS and people at risk for AIDS have been categorized. Increasingly, it seems, medical providers, public health workers, researchers, and people in general are becoming more aware that anyone, even non-drug injecting heterosexuals, is potentially at risk.

In the absence of a cure or vaccine, controlling the spread of AIDS depends solely on education and prevention. Prevention efforts are, of course, shaped by the attitudes and assumptions of those designing them, usually public health officials or members of community groups. These efforts have tended to focus on providing information and tools for risk reduction to populations considered to be at risk of exposure to HIV. Although government sponsored educational campaigns have been limited by an unwillingness to address straightforwardly issues of sexual behavior and the use of illegal drugs, there are local and community sponsored media campaigns aimed at gay men, intravenous drug users, and the public at large. These campaigns focus on modes transmission of HIV, safer sex, needle sharing, HIV testing, and early intervention. However, the fact that most of the AIDS prevention messages are aimed at gay men and drug users, along with the reality that AIDS still has not reached mainstream populations to the extent that it has affected those of gays and drug users, has reinforced the common perception that only gay men and drug users are at risk for contracting HIV. Most people still do not think themselves at risk, so do not change their behaviors, and find it easy to distance themselves from and lay blame on those with the disease/virus. They also may find it

easy to take comfort in stereotyped views of gays and drug users as morally corrupt or dirty, and somehow bringing on the disease as punishment or retribution.

The limitations of AIDS education efforts stem in part from stereotypes of people at risk for AIDS. Messages in mainstream media lead many in the mainstream to believe that they were not at risk because they were not members of these populations. This makes it difficult to expand safer sex messages to the population at large, because AIDS is associated with people with whom most of us believed we shared little.

In Risky Business: The Cultural Construction of AIDS Risk Groups (Soc. Sci. Med. Vol 38, No. 10, pp. 1337-1346, 1994), Nina Glick Schiller attempts to question the assumptions that led so many of us to feel that we were not at risk for HIV, and that allow us to scapegoat/distance people with AIDS by thinking of them as fags and junkies. She describes and critiques the use of the concept of culture to explain "AIDS risk groups" and risky behavior. She describes how initial AIDS studies focused on gay men with multiple sex partners in SF, who were then ascribed a "culture of risk" which was then generalized to include all gay men.

"Having defined AIDS risk groups as populations who are culturally different, some AIDS researchers then described these risk groups with a vocabulary that made their actions seem exotic and separate from the norms and activities of the mainstream. Thus, both gay men and IVDUs were often not described as having 'families, both the norm and cultural ideal of society... To place individuals outside the bound of family is to place them outside the human family, to dehumanize them, to turn actor into object."

She addresses this problematic approach to AIDS education by arguing that populations such as IVDUs and gay men are not homogeneous and cannot be ascribed such cultures of risk. In order to explore the extent to which people with AIDS share a "culture of risk", she interviewed and surveyed a large sample of PWAs (people with AIDS) in New Jersey. She points out that her results do not agree with established ideas about junkies and gay men.

"We found that almost all respondents had ongoing ties with their families... It is a similarity people with AIDS share with the 'general population' and an important indicator that they are culturally a part of this population."

Schiller's work serves to remind us that those of us who are not members of the "cultures of risk" cannot simply tell ourselves that people who get AIDS are different than us. She reminds us that many of us share quite a lot with PWAs. However, in her effort to refute the stereotypes of the isolated junkie and the promiscuous gay man, she displaces one set of stereotypes with another, replacing a paradigm of "otherness" with a paradigm of "just like us." By rushing to paint a cleaner, more socially acceptable portrait of people with AIDS, she excludes those who *are* promiscuous, or *do* share needles, from her world.

Both the approach she endeavors to displace and the one she offers instead present problems for health policy. If we assume that only gays and drug users are at risk, we limit the scope of prevention and educational messages, and allow everyone else to feel that they are not at risk. We also make it easier for people to believe that those who do get AIDS do so because of their own choices/cultural practices, and thus are responsible for their disease.

If, on the other hand, we think that people who get AIDS are just like everyone else, we erase important differences and may fail to make the efforts necessary to reach those who are outside the mainstream. It dangerous to assume, when designing AIDS prevention messages, that people at risk for HIV are "just like us". Most established AIDS education and prevention efforts focus on educating people on the transmission of HIV, and providing them with condoms and clean needles. Such efforts depend on the assumptions that people's primary concern is that of staying healthy, of avoiding AIDS, and that, given the information and tools, they will change their behavior. Such efforts may be ineffective in populations where these assumptions do not hold. People in the margins of society, in particular people outside the law, such as undocumented immigrants and sex workers, may have a fundamental distrust of the medical establishment and the media, causing them to believe that the public health messages they receive are not for their benefit, but are efforts to control their behavior. Although they

may consider avoiding AIDS to be important, they may also have strong, immediate pressures that outweigh their desire to stay healthy and that preclude them from adopting safer sex measures.

Unfortunately, public health efforts employed to date have succumbed to both traps. First, AIDS educational messages, by focusing on condom use among gay men and on cleaning needles with bleach, have tended to target, in content, the marginalized: men who have sex with men, and IVDUs. Such content may mislead those not targeted to believe that because they do not have AIDS prevention messages aimed at them, that they are not at risk and do not need to practice safer sex. Secondly, these educational messages, appearing mostly in English, and located in health clinics, gay clubs, and gay newspapers, have targeted, in practice, those in the mainstream: people with access to health care, who read English, come to clinics, go to gay clubs. Street junkies, immigrants, prostitutes, those who are not a part of the mainstream or mainstream gay culture, all have been largely unreached by messages so far.

Perhaps a way to avoid such traps, and to develop AIDS prevention efforts that do not reinforce stereotyped "cultures of risk", and that do take into account the complexities of people's lives, is not to attempt to characterize people with AIDS in such simple, neat categories. People at risk for AIDS, a category that includes nearly everyone, in some way or another, necessarily have varied and complicated lives. People's reasons for engaging in risky behavior cannot be summed up or generalized. Thus, there are no AIDS education messages that will be effective for everyone, and there are no media outlets that can reach everyone. Instead, a wide range of people could become AIDS educators, and AIDS educators could talk to their peers. AIDS education and prevention efforts would then be malleable, flexible, tailored for each person and different situations, so as to take into account the differences, variety, spectrum, complexities of people's lives. The Asian AIDS Project in San Francisco has pioneered such an approach.

Large studies of people with AIDS, or ethnographic accounts of "cultures of risk", are centralized efforts at deciphering or interpreting huge heterogeneous populations for understanding by a central group of policy makers, who then dictate AIDS prevention strategies that are supposed to affect/protect those huge heterogeneous populations.

Rather than such a centralized approach, AAP is an example of a decentralized approach to AIDS prevention. Rather than attempting to decode mysterious cultural others, organizers of AAP have organized people from a variety of Asian immigrant communities to provide outreach and AIDS education to their peers. They have overcome many of the barriers faced by other AIDS education groups, and have successfully reached populations that other organizations have been unable to reach.

In order to learn more about the innovative approaches taken by AAP, I interviewed four staff members of AAP about the outreach they do to various Asian immigrant populations. Dominic coordinates outreach to transgendered sex workers. Dawn works with women who work in massage parlours. Howard works with gay and bisexual men in public sex environments. Nikki works in gay bars and nightclubs.

Descriptions of Programs

1) Dawn

Dawn's position at AAP is health educator in the Women's Program. Her target population is women who work in massage parlours. "My clients are from Vietnam, Laos, and Thailand. They are all immigrants. Some grew up here, some came later. I see mothers and daughters working there. There are many single mothers. These women are the only workers in their families, and send money to family in their own countries- they take care of them as well."

Dawn and the other staff and volunteers in the Women's Program do outreach two afternoons per week, always in groups of two. "There are about twenty massage parlours in Chinatown and the Tenderloin. We might reach fifteen, and get into eight. It's a lot of

work. We provide education on general health, especially HIV/AIDS, breast self-exam, and general things. We help women arrange six month check-ups, and we advocate for them (at appointments). Also, we let them know that they can be vocal, that they have rights."

2. Nikki

Nikki runs the Bar Outreach Program, also known as the Rubber Club. This program targets Asian/Pacific Islander gay and bisexual men, as well as men who don't identify as either, who frequent bars in San Francisco. The program has been running for almost four years. Nikki identifies as transgendered.

"It's a very innovative program. It is a peer-led and peer-organized outreach program which presents risk-reduction and AIDS/HIV information through humorous skits, various contests, lip-synchs, and role plays by people in the community. We provide entertainment, a cabaret style show, and in between, we interject a message. Last year all the shows were karaoke contests, and we had an interview portion with the contestants. Now, I have an outreach character, Tita Aida— it's a take-off on a Filipina celebrity. She has a radio talk show where she reads letters, gives advice, and she also has a TV show. I call our shows, 'Lovingly Yours, Tita Aida.' I read letters about safer sex, HIV, AIDS, and other things. Tita Aida has a motherly image. She's comfortable talking with people about their problems, so they can confide in Tita Aida about their dilemmas, and I give them advice. It's funny and campy. We use humor to destigmatize AIDS and HIV."

3. Howard

Howard is 22 years old. He joined the staff of AAP in January 1994, when he was hired to run the new Public Sex Environment Outreach Program. At that time he had been volunteering in the program as a peer group leader for several months.

"A public sex environment is any public area: parks, beaches, book stores, booth stores, sex clubs, sex parties, bars, truck stops, restaurants, basically any place out of a house." Howard visits sex clubs, parks, beaches, and other public sex environments, usually accompanied by one or two volunteer assistants. Their outreach methods vary, depending on the venue. "I use different approaches. At sex clubs, I'll set up a table in the lounge area, with a badge on, and I'll walk around, if allowed. Or, if they don't want health educators at the club, I go as a patron and talk to people about sex and health practices. I also go to the parks and beaches because it's more dangerous and uncomfortable there. People are even more closeted there than in sex clubs. At parks and beaches, I carry loose condoms and lubricants, and I pass them out."

4. Dominic

Dominic does street outreach and AIDS education to transgendered sex workers in San Francisco's Tenderloin district. He approaches people on the street near bars frequented by the Asian/Pacific Islander transgendered community. Dominic estimates that of the approximately 2000 transgendered sex workers in San Francisco, over half are recent Asian immigrants. Dominic offers his clients referrals for social services, legal advice, safer sex education, and condoms. He usually works alone or with a volunteer. His is the least formal program, essentially consisting of one to one outreach on the streets. Substance abuse is prevalent but not talked about, and there is more denial about this than about engaging in sex work. Many may be high while working, which, among other things, means they are less likely to absorb information presented to them. However, Dominic has found considerable success in his work, and many clients have begun to access health, legal, and social services with the help of AAP outreach workers.

Overview of Outreach Methods

Outreach work can be broken down roughly into the following stages. First, the workers must make an initial connection with their clients. Next, the workers must be received by the clients. In order to open a dialogue with clients, and to establish a relationship with the clients, they must establish trust. They may do this by showing their commitment, by showing up repeatedly, by word of mouth from other clients. They must treat clients with respect, and show that they recognize the complexities of their lives. They must not judge the client's lifestyle, choices. Third, they provide information. The nature of this information will continue to affect their reception by the clients. This information must include more than AIDS prevention information. They must not only tell people about safer sex/clean needles and provide condoms, but they must also try to understand and address the underlying issues and problems in people's lives, that keep them in sex work, for instance, or that make it difficult for them to adopt AIDS prevention measures.

Establishing a connection with potential clients includes knowing when and where to contact them. The outreach workers at AAP don't wait for clients to show up at the agency. This is important because they want to reach people who are not already connected to the health care system, people who are, in fact, systematically excluded from accessing health care, due to their immigration status, language and cultural barriers, and/or their engagement in illegal and/or otherwise stigmatized activities. Howard goes to public sex environments to talk to people. Dawn visits massage parlours in afternoons and evenings. Dominic walks the tenderloin in the middle of the night to reach the transgendered sex worker population. He has found that the best time to reach sex workers on the streets is Friday and Saturday nights, from 10pm to 5am. As Howard explains, "I look at the population, and I fit my schedule to it. I can't just go nine to five."

Language skills are essential for establishing a connection. All four of the people interviewed are multilingual, being fluent in several Asian languages, as well as English.

Once the workers have met potential clients, they must be able to establish a relationship with them. The most important aspect here is treating potential clients with respect and without judgment. They take into account the nature of their clients' lives—whom will they trust, what will they listen to? It may also help if the outreach workers have some background in common with the people they talk to, i.e.—also being immigrants, having similar backgrounds and lifestyles, such as working in the sex industry, or frequenting the same clubs.

Howard tries to make sure clients see him as a peer. "In the field, I dress like the clients. In the parks, I wear jeans, Doc Martens. In sex clubs, I'm nude, or in underwear. I dress as others do. I make it clear to them that I'm working, so I don't have sex with them, and I never have sex with clients. But people can tell that I'm from the community." Dominic has found that the transgendered sex workers with whom he works are not always receptive to outreach workers. It has been important for him to identify the "gatekeepers" of the community who can introduce him to the girls. Dawn has meet with similar resistance from women in the massage parlours. "We're dealing with a sub-group in a sub-culture. They don't deal with people outside the business."

Because they work with people who are "illegal", because of their immigration status or their sexual activities, the outreach workers must be careful to avoid attracting attention, especially of the police. Howard describes his experiences in the parks.

"Police harass the health educators because they know what our job is. They follow a health educator, then follow his contacts. Once the contact exposes himself, he is arrested. And if a person is HIV+, then the solicitation charge goes from a misdemeanor to a felony, whether or not they are having unsafe sex. After the third arrest, there is a mandatory HIV test. So on the streets, I don't carry obvious ID, because it attracts authorities. I don't wear a uniform."

In order to open a dialogue with clients, and to establish a relationship with the clients, they must establish trust. They may do this by showing their commitment, by

showing up repeatedly, by word of mouth from other clients. Dawn explains, "It takes persistence and consistency to get trust. It especially takes honesty. You tell them what you're about, and deliver what you tell them. Word gets around." Howard agrees. "A lot of this work is centered around trust: gaining it and not betraying it. And once they trust you, they'll basically trust people you trust. That's very important for providing referrals. I can send a client to an agency, say, 'I trust him/her', and the client will trust them." Of his clients, Dominic says, "They tend to deny engaging in sex work at first, but over time, and with repeated encounters, they gain enough to trust and talk openly about their work and needs." And Nikki adds, "Gaining trust is initially the hardest barrier. People may wonder, 'What's his angle, why is he doing this?" I need to make it known to them, verbally or non, that I'm there to do my job. I'm very friendly, I smile a lot. I'm approachable and easy to talk to. Once they start talking, once I talk, there are more nonverbal signals. But if it's dark, or we can't talk, it's hard. 'He's a stranger- why is he giving me this?'"

An essential element of establishing a trusting relationship is to treat clients with respect, to show that they recognize the complexities of their lives, and not to judge the client's lifestyle or choices. Howard says, "AAP feels very Asian, like extended family. It's the way people treat each other. Staff go out of their way to make volunteers and clients comfortable. We offer coffee, food, try to include people into our family. Volunteers and clients like being part of a group, not like outsiders. It's very important for clients that they're being accepted for who they are." Dawn, who was a sex worker in Thailand for 10 years before coming to the US, finds that her experience gives her crucial insight into her clients' lives. "I understand women who are still in the business. I tell them my story, and it's compelling to them. I don't say, 'quit your job'. If a woman chooses to do sex work, I support that. As long as it's not by force." Her understanding of their situations enables her not only to gain her clients' trust, but also to help destigmatize their status as sex workers.

Confidentiality is of utmost importance, as Howard explains. "A client may be closeted about being gay, or about his HIV status. I have married clients, with kids, girlfriends, and they're not out. I must protect the client. I don't believe in outing people. I'd rather support them until they're ready to come out." Understanding how important this is to his clients, Howard takes care not to put his clients in jeopardy. "One of the challenges of the job is that it's difficult to remember my field notes. I see a lot of people on the job, at sex clubs, bars. It would help if I had a tape recorder, or took notes. But the problem is confidentiality. I don't take notes, because they could be lost or stolen. I do forget details, but it protects the clients. My view is that the client is first priority, then the job."

One of the most striking differences between the AAP outreach workers and other health educators I have worked with (including doctors and medical students), is the meaning of being "non-judgmental". Being non-judgmental is a popular goal, but to most medical people, this means not letting one's judgments show. To the people at AAP, it means confronting the judgments one has and learning how to overcome these judgments. Howard describes this: "I've seen a lot with this job, shocking things. But by keeping an extremely open mind, I can accept it. It's not me. It's okay for me not to be a part of it but to accept that others are. I respect their right to practice whatever they practice."

Howard describes the need to overcome the stigmatization that clients feel about their lives or their sexuality. "It's part of my job to destigmatize public sex environments. A lot of clients, generally, aren't out, either with their HIV status, or their sexuality, or going to public sex environments. People can say they go to bars, but there's a stigma with public sex environments: that you're not attractive enough, too horny, oversexed. It's looked down upon, and people are afraid to admit that they go. I make it clear that I go to sex clubs not just to educate, but also as a patron." Howard feels that part of his job is to help people become comfortable with their sexuality and the way they choose to express

it. "I also bring people to public sex environments if they want to go, and I'm non-judgmental, so they can talk about their fears, and other things."

Dawn expressed a similar approach, emphasizing the importance of her having a positive view of sex work. Having been a sex worker for over ten years, she understands the business, and what forces motivate a person to enter it, as well as what they can gain from it. "I think of stripping as performance. It's an art form, and also a great source of cash. It's good temporary work, always there when you need it. Strippers in the 90's are different from strippers in the 50's. It's now considered work, a job. Women find we can work this job part time, go to school full time, and get a degree. People use it to get through college. Prostitution is scapegoated as not a real job. There's a stigma in prostitution—of drugs, that you can't find a better job to do. But it is survival. I have to pay rent and bring home food, and if I do sex work, I know I'll get cash. The point is that people do it."

Once the workers have gained their clients' trust, their first message is not explicitly about AIDS, but rather about empowerment. Not only are empowerment and self-esteem important goals in themselves, but they are also prerequisites for a person's adopting safer sex and other AIDS prevention measures. Howard explains, "Not many Asian/Pacific Islanders access the services they're entitled to. Our ultimate goal is for people to access the services on their own, so they don't need an agency." Dominic offers a similar view. "This population does not seem to feel entitled to services, and is not accustomed to accessing them. It's difficult to talk about self-esteem on the streets. The word doesn't exist in other cultures. I try to convey an undercurrent of self-esteem and empowerment, by paying attention to them, providing them with a service."

Dawn's primary goal for her clients is that they will gain empowerment. She believes that empowerment has been a core element of her life, enabling her to become an activist, and that her clients' empowerment will lead to improvements in their lives, including HIV prevention. (In fact, it was through her activism that Dawn first joined

with AAP. While working as a stripper in San Francisco, Dawn organized the Exotic Dancer's Alliance, a non-profit organization advocating for stripper's rights. She soon lost her job as a stripper, and was blacklisted, so couldn't find any work. She spoke at a NOW meeting about organizing women in sex work, where a staff member from AAP met her and told her of a job opening there.) "My hope for the future is that they can advocate for themselves. A woman empowered can go on and achieve goals without barriers, will have the courage to fight it, and change for the better. It happens slowly. They can make decisions on their own. If they get married, they can talk back. They can talk back to doctors, too. I do it for them now."

All of the workers I spoke with understood that it was important to address the clients' immediate needs, rather than just pursuing an agenda of AIDS prevention. Howard describes AAP's prevention and education efforts as, "holistic-STDs (sexually transmitted diseases), universal precautions, general health care, sexuality, coming out, family issues, drugs, jobs, homelessness." They ask, "What can I do for this person that would be the most useful to them?" Often it isn't to provide information on safer sex. Explains Howard, "People have more pressing issues to deal with. HIV won't kill you immediately, but starvation and living on the streets will. So we deal with these before broaching HIV." And Dawn, "Our goal at AAP is health. But for these women, other needs come first. Their immediate needs are for me to listen, understand, and provide moral support. We deal with legal issues-- immigration, prostitution. They may need a clinic appointment, test results, for me to pick them up and take them to the doctor. And simple things- even things natives think are simple can be difficult for a new immigrant. A woman might have menstrual cramps. I tell her that there is Advil for cramps, take her to the drug store, show her how to buy it, tell her, 'this is okay, you can take this'. We try to make it convenient, easy." And Dominic: "The girls are most eager to deal with their most pressing and immediate issues. For example, they often want legal assistance and information: What are the implications of arrest, especially for non-citizens? What

should they do, and how should they plea if arrested? Do they have any legal recourse for dealing with abuse by policemen?" In many cases, it is only after establishing a trusting ongoing relationship with his clients, often by providing legal information and referrals, that Dominic is able to communicate with his clients about their sexual practices and risk behavior.

Thus, rather than adhering to a set protocol for outreach work, they tailor their methods and content of their messages to specific situations, as well as to the needs of their clients. Howard tends to start with casual conversation. "I start with, 'hi, how are you.' If they're accepting, I identify myself as a health educator. 'I can provide you with services, take you for testing, jobs, housing services, referrals.' If not, I talk as a peer." In the later case, Howard introduces the AIDS education messages more casually. "I've heard this behavior is dangerous. Did you know that?" At parks and beaches, Howard uses a different approach, and provides different kinds of information. Michael, my coworker, carries packages with food, gum candy, condoms and lube. People eat or chew gum to erase the taste of semen. And we let people know it's dangerous- the police do come. We disseminate information- this is a safe place, this is not. We warn people about shootings, police raids, police entrapment, harassment, about when it's no longer feasible to cruise there." Dawn adds, "I base my outreach on what I see-- women who don't get their needs met. I ask, 'What does the client need, and what are the needs in the community?' I think this work is successful because we provide the language, and advocacy how they want it, not how we want it."

The workers exercise flexibility in tailoring their methods, and learning from what they see. Howard describes the genesis of his program. "AAP had been doing outreach in gay bars for three or four years, and we figured out that after the bars, people go to public sex environments. So it was logical to go to public sex environments and continue the HIV education message.

The workers also emphasize that beyond addressing immediate needs, it is important, although difficult, to address the underlying problems in

their clients' lives. Dominic works with the group that faces the most problems, and whose problems are the most difficult to address. Many Asian transgendered sex workers resort to survival sex to acquire the funds necessary for surgery or to support their families, or simply for survival, as other modes of employment are unavailable to them. This issues and difficulties with which this population is faced are tremendous. They have a hard time accessing social and health care services. They face job discrimination, and they require a steady supply of hormones, which is difficult for people without steady incomes, and further contributes to people becoming trapped in survival sex work. They lack access to legal services. Transgendered people have a high rate of suicide and resorting to sex work, especially if they come out early in life before they are able to become established with money and support.

Clearly, for this population, AIDS prevention messages are not the only answer. They may provide people with basic knowledge on safer sex, but they do not address other issues that take greater importance. For example, first-time convicted prostitutes receive mandatory AIDS education. Many of them are tested every few months for HIV at anonymous testing sites. Dominic explains that even though the sex workers with whom he works tend to have a lot of knowledge about AIDS and safer sex, they do not or cannot practice safer sex regularly. "Survival is the bottom line. If they are offered more money for unsafe sex, they will do it. This happens a lot." Furthermore, although clients acknowledge their risk for HIV from customers, it is a different issue to get them to use condoms with their primary partners—usually boyfriends who are also often their pimps, or act as pimps. Thus, effective AIDS prevention work requires more than condoms and instructions on how to use them. Unfortunately, the issues beyond safer sex education are complex and difficult to address. Dominic confesses that because he is unable to address the underlying problems, sometimes his role is limited to that of condom dispenser.

Dawn does try to address some of the underlying problems with the women in the massage parlours, by talking to them about other employment options. "Sex work is

temporary. I try to help them prepare for when they're ready to get out. They do have labor skills, they can work as massage therapists. They don't have to start over totally."

While they do try to address the underlying issues in their clients' lives, the workers also speak with their clients explicitly about their risks for HIV, and prevention measures they can adopt. However, they understand that people's reasons for engaging in behaviors that put them at risk for HIV are varied and complicated, and cannot be addressed simply by providing safer sex information. Howard explains, "There's much denial in the community. People may not even realize that they're doing something. I talk to people. They may need to say it out loud for them to realize they're doing something, or to realize the implications of what they're doing." He understands that even if a person decides that they want to change their behavior, it may be difficult for them to do so. He cannot simply tell people what to do. Unlike his medical counterparts, he doesn't insist that his clients change their behaviors, or try to scare them into doing so. Rather, he sees that it is the client who controls his own behavior. "I tell them how to stay healthy, if they're positive, or how to stay HIV negative. I make sure they understand the implications, have information, then I let them decide. It's up to them to follow through."

Recent reports indicate that many gay men are returning to engaging in unprotected sex. This has been partly attributed to the narrowness of safer sex messages, which say that everyone must use condoms everytime. They offer no room for negotiation, and may contribute to a person's feeling like a failure for having had unsafe sex, then lead to a fatalistic attitude that may cause them to give up altogether on safer sex because they can't be safe every time. At AAP, outreach workers try to take this into account. As Howard explains, they also understand the limitations of education. "I need to draw the line somewhere. Information is good, but too much of anything, including information, is bad. I don't want them to think that anything they do will infect them. I need to offer support as well as education. I'm a caregiver."

Unlike some of their counterparts in mainstream medicine and public health, these workers do not see themselves as heroes or saviors. Howard says of his role, "I don't believe anyone can't live without me. Rather, I'm here to share information. I'm just here as a friend to talk to, to provide services if you need it, a source of referrals if you need it. They'll survive without me, but I'm there to help."

That they have access to these communities is important not only because they are able to offer services, but because they can also conduct research, begin to document that these populations exist. This is important because these groups are difficult for more mainstream researchers to study, and research information, such as numbers of clients served, profiles of the populations, are essential for the agency to secure funding, and also to inform some of the centrally dictated public health policies.

Rubber Club, Nikki's bar outreach program, has attracted hundreds of attendees to its popular bi-monthly shows. Nikki incorporates research aspects of her program into each event. "Surveys are conducted to the attendees, which enables AAP to recognize what the community needs are, in terms of effective intervention, sexual behavior, and to gauge the community's knowledge of AIDS/HIV. The Rubber Club also provides a venue for recruited peer leaders to be introduced and to interact with co-peers and act as role models to them. It has also been very beneficial to the agency, for it brings in potential donors." Dominic explains that his clients appreciate his efforts and concern, and so are honest in speaking with him and willing to participate in research and evaluation surveys.

In addition to reporting of the advantages of their methods of outreach, some of the workers also described limitations of the work. Howard says, "I want to help as many people as possible, but I need to recognize that I can't help everyone. Some don't want services. Some still become HIV positive after hearing our talks. But we can't internalize it or blame ourselves. We need to express and release it." He emphasizes the need for the workers to support each other, and to make sure they take care of themselves. "This

job is really hard. To deal with people with AIDS, clients, friends may die. Clients become friends. Five died this year. So I need emotional support, to recognize my limits, both personal and on the job. The work brings up many issues. It can cause my emotional well-being to go off-balance. I need to talk, confidentially, with no names, about clients, feelings about this job."

Those workers who do their outreach work in the streets face added dangers. "I need to keep myself and the volunteers safe. I tell them, if someone attacks you, defend yourself. We'll deal with the ramifications later. I give them cab fare to get home. If you feel unsafe, leave. There is danger on the job. You have to use street savvy, especially with late night work. The venues are not in safe areas of the city."

While all of the workers agreed that the work is difficult, they also reported that they feel that they have made important differences in their clients' lives. This is difficult to quantify, especially because most of the workers do not take field notes, but as Nikki comments, "Most people don't give credit to this community, but people do pay attention, and they do remember."

Conclusion

From these few examples from one organization, it is clear that any attempt to either formulate policy on the basis of simple categorizations or to dispel such stereotyping in a similarly sweeping manner (such as was attempted by Schiller in her study), is doomed to miss the complex texture of people and populations at risk for HIV. At AAP, through a process of individual program development constructed on the streets, in the parks, in the sex clubs, a relatively coherent basic underlying approach has been established. By using this flexible, decentralized approach, workers at AAP have been able to reach and interact with populations unreachable by conventional public health outreach methods. The women who work in Tenderloin massage parlours do not read or speak English. Many are in this country illegally, and are engaged in illegal activity--sex

work. They have a distrust of establishment and may fear arrest or deportation. This approach takes these complexities into account. By acknowledging that many people cannot simply adopt AIDS prevention measures as handed down from above, they open up communication. Only by doing this do they make it possible to begin to address AIDS prevention.

The basic premise of this type of work is that there is no single specific set of methods, no one model, that will work for every population. However, there are basic themes common to all the people I talked to, common philosophies or guiding principles that have been effective for outreach workers working with diverse people in multiple settings. What follows is a summary of these underlying themes.

Strategies towards a decentralized approach:

- 1. Recognize that people's lives are complex, that people have complicated reasons for engaging in 'risky behavior', and that avoiding HIV may not be their top priority.
- 2. Messages and outreach methods should be flexible, adaptable, depending on the person being addressed and their situations should be taken into account.
- 3. Outreach should consist of comprehensive measures addressing whatever a person's most immediate needs are.
- 4. Outreach should be empowering in order to be effective. In order for people to give avoiding HIV high priority in their lives, they have to feel that their lives are worth living, and that they deserve not only to live, but to access the services that may help them to avoid AIDS.
- 5. Outreach messages and approaches should be designed by many different people in different situations. It would help if the workers came from the communities to which they provide outreach. This helps because such people are likely to know firsthand what issues their peers will face, and will know better how to communicate, and will more likely be trusted and therefore listened to.

- 6. Outreach workers will have to talk about more than AIDS. They will, as mentioned above, have to address the immediate pressures that may preclude a person from adopting preventative measures.
- 7. In order for outreach workers to learn who their clients are and what their specific needs are, they must have a "listening heart"; that is, they must be open to observing and learning about and participating in their clients' lives.

Schiller is correct in pointing out that some of the people who are at risk for HIV are people who do not fulfill the popular media stereotypes of those who gets AIDS—junkies, faggots, and whores. However, it is disturbing that her attempt to displace the notion of high-risk cultures, notions perpetrated by mainstream media, actually plays right into the mainstream in focusing attention on those who are within it.

The fallacy of her conclusion lies in her overwhelming selection bias. By choosing her sample of people with AIDS from health clinics and agencies, she included only those who were enough in the mainstream that they had access to social support. She could never have gotten access to the clients at AAP, or other populations who exist on the edges of society, such as illegal immigrants or prostitutes. At AAP, Dominic worked for months to gain access to his clients. Perhaps Schiller never imagined the lives of these people, but even if she had, they never would have spoken with her. She says that people with AIDS are just like us, but she only ever had access to people who were just like her in many ways. In epidemiology, we call this selection bias. While her message, that people with AIDS do not necessarily belong to "cultures of risk", and in fact may live in mainstream cultures, is an important one, it is misleading and false to generalize these findings to include/describe all people at risk for HIV. This problem underscores the need for a decentralized approach to knowledge production.

IV. Policy Implications of Asian AIDS Project's Outreach

Asian transsexuals, in particular immigrants, tend to differ from the American profile of transsexuals. American transsexuals are mostly gender dysphoric: men identifying as women. Most Asian immigrant transsexuals, on the other hand, identify as men, even after sex reassignment surgery. They tend to have gone into sex work as a means of survival. They get more attention, tricks, and money for being transsexual. More attention from men helps to raise their self-esteem, and they are in this manner encourage to take hormones, dress as women, and try to "pass." During the transition period, though, they might not have a clear gender identity. They identify as men internally but as women externally.

This issues and difficulties with which this population is faced are tremendous. They have a hard time accessing social and health care services during the transition period (which, it should be mentioned, can last indefinitely). They face job discrimination and may resort, as a result, to survival sex. They require a steady supply of hormones, which is difficult for people without steady incomes, and further leads to people becoming trapped in survival sex work. Transgendered people find it difficult to access social services, and few of these services are sensitive to their needs anyway. Many purchase hormones on the streets, and receive treatment from "fly-by night" MDs, who sell hormones and inject free flowing silicone into their breasts. They lack access to legal services, which is significant because so many face abuse by the police, cannot or do not report rapes because of judgments that they cannot be raped or deserve it or ask for it, or that it results from an illegal transaction gone awry. They are not included in research and epidemiology, so little is known about their behavior and risks. They would benefit from counseling and support groups, but funders for almost any community service require information on numbers of cases, but transgendered people are usually classified with gay men if at all, so they are an invisible population, there are no numbers with

which to fight for funding. Transgendered people have high rate of suicide and resorting to sex work, especially if they come out early in life before they are able to become established with money and support. Many Asian transgendered sex workers resort to survival sex to acquire the funds necessary for surgery or to support their families, or simply for survival, as other modes of employment are unavailable to them.

Most established AIDS education and prevention efforts focus on educating people on the transmission of HIV, and providing them with condoms and clean needles. Such efforts depend on the assumptions that people's primary concern is that of staying healthy, of avoiding AIDS, and that given the information and tools, they will change their behavior. Such efforts may be ineffective in populations where these assumptions do not hold. Prostitutes are engaged in illegal, stigmatized activity, upon which they depend to survive. They may have a fundamental distrust of the medical establishment and the media, causing them to believe that the public health messages they receive are not for their benefit, but are efforts to control them. Although they may consider avoiding AIDS to be important, they may also have strong, immediate pressures that outweigh their desire to stay healthy and that preclude them from adopting safer sex measures.

An examination of illegal immigrant transgendered sex workers illustrates the limitations of existing services and the public health policies guiding them. In public policy and program design, there is a tendency to group people and services according to gender, race/ethnicity, culture, immigration status, age, sexuality, HIV status, and other divisions. While such classification simplifies the work of policy makers, funders, and service providers, it also arbitrarily divides people into categories which in many cases do not adequately reflect their situations or address their needs. People who fit into several categories must access services from numerous sites, and those who fit into no category may be excluded from accessing any services at all.

Transgendered sex workers, particularly the immigrants, cross many of the boundaries set by health care and social service agencies. Services exist for Asian immigrants, but most of the agencies providing them are unprepared to deal with issues of sexuality. Most gay organizations refuse to deal with transgendered people, whom they may not consider to be gay, or who they may consider an embarrassment. Medical providers lack knowledge about the effects of hormone therapy and silicone injections on people with HIV. Legal service providers for sex workers lack expertise on immigration issues.

Transgendered people in general face unique problems because of their ambiguous gender identity. Emergency shelters require proof of gender. Transsexuals who do not follow the medically established route of transition (through psychiatrists, diagnoses of gender dysphoria, prescribed hormone therapy, living one year as the desired sex under medical supervision, sex-reassignment surgery) cannot get the needed documentation. They are often refused medical care at clinics, where doctors may chose not to care for people of ambiguous gender. They face job discrimination, not only because of their immigrant status, but because few people are willing to hire transsexuals in transition. Even if they could find employment, their health insurance would probably not cover their hormone therapy or sex-reassignment surgery.

It would be unrealistic to attempt to establish separate services targeted to each sub-population. Even in a group of people as seemingly narrowly defined as transgendered sex workers, there is great variation in identification and needs. Instead, it should be recommended that existing service providers make efforts to be inclusive of people who do not fit into defined categories. The argument might be offered that "southeast Asian immigrant, pre-operation transgendered sex workers", for instance, constitute such a small category as to make any special attention directed their way efforts poorly spent. Perhaps this is true when considered from this narrow perspective. It is for this very reason, that is, to illustrate an extreme case, that I selected the populations

studied in this investigation. There are many such populations, but it is not only these that are affected. Perhaps as important as the implications of this level, I suggest that the prevailing mode of demographically based public health research and service provision is guilty of a reductionistic bias which restricts its effectiveness.

V. Reading medical interactions against Asian AIDS Project outreach methods

Rather than discussing the clients, their lives, their tragic stories of how they ended up being sex workers, in this paper I want to focus on what we as medical providers can learn from the outreach workers at AAP, so I want to get away from the paradigm of telling tragic tales, and to focus instead on the outreach methods, being flexible and adaptable, and learning lessons from people in related fields.

I realize that outreach workers and doctors have different jobs, so when I say that we as medical students and doctors can learn from outreach methods, of course I do not mean that we can take their methods and apply them directly to what we do in patient encounters. In fact, I want to emphasize that there are no simple answers or easy solutions forthcoming in my paper. But I do think that there are many points to be made, a lot we can learn by reading medical interactions against the AAP outreach methods, thus bringing to light the finer points of each.

Few of these points can be made by comparing directly the approaches of AAP outreach workers and of doctors and medical students. The contrasts are too great, and it is difficult and problematic to make direct comparisons, since their jobs and roles differ so much. For example, the AAP outreach workers are peers of their clients, whereas doctors and patients are rarely peers.

Recall the story of Howard, naked in a sex club, talking to people as peers and offering them information, in a casual and concerned manner, about safer sex. Now consider a typical doctor-patient interaction. A patient is taken to an exam room. This room is full of artifacts of medical culture, and may have walls lined with Latin-scripted and political leader-inscribed certificates, sparkling with gold seals and authoritative authenticity. Who owns the space? Who's culture dominates? What is there of the patient's culture? What is the hegemonic viewpoint in that room? That patient is greeted, one to twenty-five minutes later, by a doctor, who opens the door as he/she knocks. The

doctor is easily identifiable by his or her white coat and confident demeanor. After a brief conversation, during which the doctor may ask the patient about sexual activity, and may warn about the importance of safer sex in the age of AIDS -- a message with an implicit threat of death -- the doctor may instruct the patient to undress. If the patient is a woman, the doctor may say to her, "You can leave your bra on."

Of course, I'm not suggesting that to try to be more like Howard, we should undress with our patients. My point has to do with the fact that Howard does whatever he has to reach his clients--he works on their terms. We work on ours. This, in and of itself, may not be a bad thing. But being aware of this fact is important. Every time you think about being inconvenienced by a patient, the fact that the entire interaction is on your terms should mitigate the inconvenience.

Let's also consider Dawn and Dominic, exploring the complexities of their clients' lives, emphasizing the importance of learning of and addressing their clients' immediate concerns first, and of establishing a trusting relationship before broaching the subject of AIDS. Contrast this to the doctor who resents having to treat patients who are noncompliant, who can't keep their health together, who have hypertension yet don't take their meds and can't quit smoking and keep eating Chinese take-out (read greasy and salty), spilling soy sauce on their slothful unregulated bodies, offending the sensibilities and thumbing their noses at the pious good intentions of their compassionate-untilpushed-to-the-edge physicians, who certainly mean well but can hardly be expected to be gracious about squandering their extremely valuable and highly compensated time on the self-induced and partially deserved MIs of slovenly pigs like you. This was a case presented in class, though in a slightly different form, to evoke feelings about the frustration providers can feel, particularly with 'difficult' patients. My question: Can we find a way to acknowledge doctors' burn-out/ frustration without demonizing patients? Let's please not fall into the trap of us vs. them. Try to understand that there are forces greater than us, issues more important than our own egos, how the patients 'make us feel'.

Most of what we can apply to medical interactions from studying AAP approaches is not in the form of direct comparisons or specific techniques that can be transferred from one setting to another. Rather, it is in the underlying approach, the ways people position themselves in relation not only to their clients/patients, but also to other actors in the social, cultural, and political realms. In the next section, I will explore some of the observations and analyses I have made about medical culture and medical interactions. These have been informed by my work with AAP, but there will be no clear or direct connections to the work described thus far.

VI. Prescriptions and Palliations: obscure(d) meanings, strategic reflections, and illuminating subtexts

My larger project is a critical analysis of our actions as medical providers and as humans. When I say critical analysis, I don't mean criticism as in putting one's self or others down, or seeing things only in a negative light. I mean, as Gayatri Spivak describes it, "criticism in the robust ... philosophical sense"; that is, examining in depth and with diligence the actions we take and how we decide to take those actions. My goal is a transformed medical practice, wherein I, and others, I hope, carefully seek out and make valiant efforts to resist the reproduction of oppressive practices in medical interactions. By oppression I mean all kinds of oppression. Though I may use the terms racism, sexism, homophobia, it's important to remember that these terms can't encompass the multiple and complex forms oppression takes, and that these various forms of oppression rarely act independently. My goal is to make valiant efforts to resist reproducing oppressive practices of all kinds. I'll start by explaining my title.

Let's start with the first word, "Prescription".

prescription n 2: the process of making a claim to something by long use and enjoyment 3: the action of laying down authoritative rules or directions 4 a: a written direction for a therapeutic or corrective agent b: a prescribed medicine

We tend to use the 4th definition of this word. But, if we expand our gaze just a bit, we can see that this word has other meanings relevant to our roles as medical providers. We can do the same thing with the next word, 'Palliate".

palliate vt 1: to reduce the violence of (a disease): ABATE 2: to cover by excuses and apologies

We tend to use the 1st definition here. But expanding our gaze, we find another useful meaning, again very relevant to our roles as medical providers.

These are symbolic examples, but they are not only symbolic. I want to point out that by looking further than usual, and not necessarily a lot further, we can uncover meanings we hadn't before seen, meanings that can guide us toward the goal of a transformed, antiracist, anti-oppressive medical practice. Now to explain the rest of my title.

My aim is to uncover meanings that have been obscured and the ways that we actively obscure them. I want to use stories and anecdotes to aim strategic reflections, as from multiple hidden mirrors peeking out when we least expect them, to flash back on us our own reflected images, so that we sneak up on ourselves, catch ourselves in acts we tend to deny, at moments when we tend to blink. I hope to illuminate, and learn from, the subtexts of my project and of the medical interactions I will describe—the conceptual frameworks and theoretical foundations that underlie medical interactions, doctor-patient encounters, and conversations and silences in medical school classrooms.

I want to open up an awareness of the multiple consequences of the things we do as medical students and doctors. This is not the same thing as saying we shouldn't do those things. I've noticed a tendency not to ask why we do things. Often in classroom discussions, questions like, "Why are we discussing this?", or, "Why was this article assigned?", are taken as challenges, to mean that we should not be discussing this, or that the article should not have been assigned. It's as if the need to question a purpose exposes a lack of justification, that if the reasons for doing something are not so clearly and immediately obvious to everyone in the room as to go unspoken, then there isn't reason enough to justify doing that thing. I want to encourage a moving away from this fear of questioning. Let's ask of *everything* we do, "Why are we doing this?"

We may also be reluctant to question our actions because we tend to assume that a given action must be either good, and kept, or bad, and discarded. Thus, we fear that if we question an action, and we find anything bad about that action, then we'll have to stop doing that action altogether. But this isn't the case. There are many things we do as medical providers that are extremely useful, things without which we couldn't do our

jobs, that have potentially bad aspects to them. Because something has a potential danger doesn't mean we can't use it; it means we should look for dangers and be aware that they do exist in things that are also very useful. It is important for those of us who are committed to fighting racism to look for and acknowledge these dangers *especially* when they are a part of things that are extremely useful.

I'll be the first to admit that such questioning can be painful. It's no fun to acknowledge ways we're complicit with racism and other forms of oppression. We don't like to think of ourselves that way. But unless we make these acknowledgments, unless we pursue this project, we will not effect change, but will rather go on blindly following, unknowingly perpetuating oppression.

Every action we take, in our role as medical providers as well as in every other role we assume, has multiple outcomes. We need to get away from simple binarisms, so that a given action in a given context is not either good or bad, does not either help or hurt the patient. Rather, each action has multiple consequences, some of which we might consider to be better, others worse, but that each of us will consider differently. I think it is important to examine these multiple consequences, whether we like them or not. Some of these consequences are obvious, the ones we tend to see, and others we probably won't ever know about. I am concerned with those we won't see unless we look really hard- the finely woven threads. We tend to measure the success of our actions in the medical arena in terms of certain outcomes: will it make the patient's illness better, will it ease their symptoms or improve their health, will it not cause them pain, will it be affordable, etc. But we rarely look beyond these immediate measures, to ask questions like:

- •What's at stake, here, and for whom?
- •On what assumptions am I basing this action?
- •Are those assumptions valid?
- •Will this action reinforce the status quo?

- •Will this action in any way, to any degree, perpetuate, exacerbate or reproduce racist oppression or other oppression?
- •Is this action revolutionary or challenging?
- •What am *I* getting out of this?
- •Am I furthering my own goals, which may or may not all be consistent with the goals I have for my patients and that my patients have for themselves?
- •Is there another way to do this that would favor me less and favor a patient or another goal more?
- •If I have conflicting goals, which ones or whose will I favor?
- •What constraints do I imagine have been placed on me in deciding on this action?
- •How real are those constraints?
- •Is it possible, in this situation, for me to act differently?

In other words, let's try to be mindful and accountable. Let's take responsibility for our actions.

One way to begin addressing these issues in the medical arena is to examine medical culture, and the ways we participate in this culture. By medical culture, I mean the way we regulate our behavior. This regulation doesn't necessarily come after we act. It produces our actions, because we decide what we are going to do or think or say according to a set of unspoken rules that we have learned outside of us, by watching our role models, our teachers, by seeing how they react to other actions. We perform these habits actively, but not fully consciously. So before we ever take an action, the regulatory forces of medical culture are acting on us. It's when we go along with this without thinking that we participate in reproducing this medical culture unchanged in form. But if we pay attention to what we're doing, how we reproduce the culture, then we'll have a chance of subverting elements of that culture that are oppressive.

To introduce this, I'll start with the prior quote from Emily Martin. In the introduction of "The Woman in the Body", she says, "Although I will be critical of many central ideas current in medicine because I think they are demeaning to women, doctors as individuals are certainly not to be held responsible. Medical culture has a powerful system of socialization which exacts conformity as the price of participation." I agree that medical culture has a powerful system of socialization, and that conforming is the path of least resistance. But I absolutely disagree with her assertion that individual doctors are not to be held responsible. This medical culture does not simply exist outside of us. Rather, we participate in reproducing medical culture every time we act as medical students and as doctors. And this is true not only in patient interactions, but also in the classroom, an important site of knowledge production, where we construct our truths. We construct truths about clinical practice, but also about the way we see the world, the way we see our patients. Some of the truths we construct we are aware of, but probably far more of these truths take root without our conscious awareness.

In order to explore how this works, I am going to use as examples, situations from my experiences in JMP. I want to make it very clear that this is not about singling people out or judging anyone's actions. I have no interest whatsoever in policing others' actions. Rather, this is an effort to examine these situations to see what we can learn from them. I don't intend for any of this to be personal. I heard someone say the other day, "It's always personal," in response to a discussion of the principles behind people's actions. But to dismiss social or cultural critique as personal is to shut down meaningful discussion. I advocate instead for a free exchange of ideas without allowing insecurities to demote broader ideas to a petty focus on the personal. I think that we need to be able to take a look at what we do, to learn from our experiences, and what I'm going to talk about are some of those experiences.

In class one day, our guest lecturer told us that county hospital patients are unreliable, and that you can't believe what they tell you. He said this, and some students

looked around the room, acknowledging to each other, albeit in silence, that they disagreed with this assertion. People didn't look comfortable. Our regular instructor said nothing; so after a few moments, I turned to him and asked, "Are you going to allow this in your classroom?" I got no response, which I took to mean, 'yes'. This isn't how the situation ended, but for right now, I want to explore this moment in the story, when something bigoted and hateful has been asserted by a guest lecturer, and the regular instructor and the students are all silent.

Of course we all know better than to believe such crude stereotypes, so none of us is going to consciously adopt as our point of view that county hospital patients lie. So, what's so bad about this silence? Why not just let this slide? After all, this person has generously donated his time to come teach us today. He is a colleague of our instructor, and none of us wants to harm that relationship. Some of us may even feel that confrontation would be rude. So what harm has been done by this silence that meets his claim? As I have said, the workings of knowledge production are subtle, and often operate at a level below consciousness.

First, it's important to realize that this silence is complicitous. The silence grants leeway to his statement, "county hospital patients cannot be trusted to tell the truth", and allows it to fill the room and our minds. We can counter his statement consciously, by thinking to ourselves, "That isn't true." But the very spokenness of his statement grants it access to portions of our minds that are beyond the reach of conscious thought. To fully analyze this process psychoanalytically would be beyond both my training and the scope of this presentation. But accept for a moment, that this experience, added to other experiences, creates our mind's eye, our world view. It is the historical composition of the lens through which we see, and hear, and feel, and come to understand our world. In his Prison Notebooks, Antonio Gramsci writes, "The starting-point of critical elaboration is 'knowing thyself' as a product of the historical process to date, which has deposited in you an infinity of traces, without leaving an inventory. (Gramsci, the Prison Notebooks)

Now, what I'm talking about here is one of those traces. It's important to keep in mind that there are, as he says, an infinity of traces. Our lifetime of unconsciously collected experience forms a filter, a lens through which our perceptions are shaped. Every experience can become one of these traces that shapes the way we view the world, every experience enters and adds to this unconscious filter. So though we are only talking about one of them, this example should be taken as part of the greater context of creating an unconscious filter through which we see the world.

So while we might recognize that this guest's comments are offensive and wrong, and none of us would ever think or say such a thing, if there is no intervention, then we also have this episode added to our understanding of our roles as doctors, what thoughts are sanctioned, and when we're supposed to be silent, when we're supposed to let bigotry go unchallenged. This new experience adds to our knowledge of what it means to be a doctor, and how doctors are supposed to act. And though this might not cause us to go out and commit overt acts of bigotry, it will undoubtedly affect us somehow. As I have described, our perceptions, and I don't mean our opinions or thoughts, but what we are actually able to see, hear, and feel, are shaped by our prior experiences, what we learn to expect, what we are taught to listen or look for. So the danger of letting this kind of bigoted comment just slide, is that it will shape our perceptions and affect the way we are able to see and hear, in this case, county patients, in the future. And we might never be aware of how such incidents will have shaped our perceptions. No matter what we believe, or how much we disagree with him, even if we tell ourselves that we are going to ignore his comment, when we let this moment go by, we are allowing it to enter our collection of experience. Whereas, if we intervene at that moment, draw attention to what he has said, state out loud why we disagree, and initiate a discussion about it, then the entire experience, and this man's comment, enter our collection of experience in a very different way.

And what makes all of this especially dangerous is that *this* insidious learning process acts in concert with *another* insidious learning process, wherein we create and reinforce our own sense of goodness.

To illustrate this second learning process, I'm going to present a quick generic classroom scenario that has come up many times, and not just in the JMP. It goes something like this: A student tells a story about their experience with their preceptor or some other doctor. They go to see a patient, usually a black, or other ethnic minority patient, maybe a black patient who uses crack, or an Asian immigrant who doesn't speak English. The doctor is a real jerk. He, it's usually a he, treats the patient in a blatantly bigoted way. Sometimes, the student is able to rescue the situation by reassuring the patient.

We hear this story all the time. What's going on here? We have a bad doctor, a victim/patient in need of rescue, and a room full of students who are eager to fill that need. What transpires in the telling, and in the collective vicarious experience, is that we create a sense of our own goodness.

Breaking down the world into simple binaries allows us to place ourselves automatically on the side of goodness and righteousness. (Many of the students now in medical school grew up in the Reagan-Bush years, when it was easy to think in terms of good and bad. The politics and policies of those administrations were so clearly "bad" to many of us: the bad Republicans didn't care about the poor, the needy, the people in need of health care. Everyone else, us, the good people, did care, so everyone else became good. Combine this with privileged upbringings, constant reinforcement for getting good grades, for being "caring" because we volunteered in the hospital once a week, and it is no surprise that the students of today do not question their status as do-gooders. They have never had to question anything they have done, and they are not going to start now, for nothing has changed for them. They are still being rewarded for doing things that make them look good in the name of the underclasses, the needy, the pathetic.) The

binary of good and bad allows people to assume that because they mean well, they are doing good. Because they want to "help people", they must be helping people. However, what happens when we explore the nature of this help? What conditions does it entail? Who are the people being helped, and what does that help look like?

We bond, establish a camaraderie over our stories of insensitive doctors. Simply by recognizing the bad behavior of this doctor, we position ourselves as good. Because those of us hearing the story commiserate, understand, and empathize, we experience a vicarious affirmation of our goodness, an extension of goodness to everyone in the room.

We are also reinscribing the patient's societal role as downtrodden and in need of our rescue. When we construct our identities as liberals, as doctors who help people, there necessarily must be a population of people who need help. When we project these things on patients, when we imagine them as lowly and pathetic, we are also opening ourselves up to hating them. In such cases where students emphasize the abjectness of their patients, we distinguish ourselves from them, we dehumanize them. We put them in a place that is useful for us, and we ignore who they really are. (Contrast this to other patients who we may identify with and describe as "sophisticated" and "educated" and "articulate". In my experience these are euphemisms for, middle class, white, and speaks without an accent.)

Moreover, many of us students coopt the oppression, turning it into a situation where we are oppressed, having to stand up to bad oppressive doctors. In protecting the oppressed from the evil doctor, the students become the heroes. The patients remain oppressed, conveniently ready for the next oppression for the next medical student to coopt. When we cling to simple binaries, it can become threatening for us to hear of someone else's oppression. We think to ourselves, I certainly cannot be on the bad side of this equation, so I must be on the good side. Then we as caring medical students get to claim the status of oppressed, get to speak for all oppressed people, and can feel absolved of all responsibility we might actually have for the racist situations others face. (An

amazing example of this was the reading of Maya Angelou's "Still I Rise" by my classmates to last year's graduating class. By reading this poem about overcoming the legacy of slavery to a group of young people (none of whom were black) about to enter one of the most privileged ranks in our society, they equated the difficulties of medical school with the legacy of slavery. How might they understand the experience of people who face racism daily, not perceived oppression analogous to racism, but who must face racist behavior daily?) I believe that these liberal do-gooders do mean well. I just hope that we can learn to examine what we are doing, and whom we are really helping when we raise ourselves up at the expense of our colleagues and patients.

This is our moral education, and it is a deceptive one. It may make us feel good to do this, but this is an easy way out and one that doesn't require us to look very deeply.

Once we have established that we're good, what is there left to discuss? Where is the impetus to be really critical? All we're doing is demarcating the extreme limit of bad behavior, and making sure we're on the good side of that very bad point. But it's easy to be better than a racist bigot. And that's all we're asking of ourselves if that's where our analysis ends. I want to encourage us to do better than that, to be brave enough to delve further, to question what we might have in common with this bad doctor, what compels his action, or whether we have done similar things, especially in similar situations, or how we are complicit with such an oppressive system. We could question why it's always we who are good and always others, others not in the room, who are bad. We could ask ourselves what circumstances might lead us to act in a similarly "bad" way. Remember that we are part of a long tradition of liberalism, where we purport to be 'helping' people while keeping them in their abject position, elevating ourselves to the level of hero, thus making our reaching down to help so much grander a gesture.

This plays out in the ways we are tested, also. In our course on sexual issues in medicine, we read, talk to, and see movies portraying sexuality of various groups-people with spinal cord injuries, gays and lesbians, s/m practitioners, men with impotency, etc.

Our final exam in this course consisted of the following questions. There was a list of various patients: a transgendered person, a lesbian who practices s/m, an elderly woman. We were asked to describe two stereotypes about each patient that might impact negatively on their health care. Here again, we are asked to imagine how a bigoted person might see these patients. We were not asked for two things we might do to ensure that these patients received the best possible health care. We were asked rather to imagine what some bad person might think about them. This is not much of a challenge, and may serve only to reinforce the negative stereotypes in our own heads.

So taking these two scenarios together, not only is this bigoted remark about county patients integrated into our perceptual lens, but at the same time we are learning to see ourselves as really good people, not vulnerable to thinking bigoted thoughts, or to seeing people in a bigoted way. Thus are we trained to tolerate hate and at the same time trained never to think of ourselves as hateful people. Here's a quote from Patricia Williams regarding this:

"The result will be students who are cultured to hate, yet who still think of themselves as very good people, who will be deeply offended, and personally hurt, if anyone tries to tell them otherwise." (Williams, 1994, p. 87)

I think this is an important point. If we feel this offense and hurt, we are unlikely to be in the mood to question our actions. And why is it so important for us to go through all of this trouble of questioning our actions anyway, — to try to harness traces, — to delve into what isn't readily available to our conscious minds? In his book "Racial Healing", Harlon Dalton makes an important point. He writes, "Good White People are more responsible for preserving the racial pecking order than are the relatively few jerks who spew venom or act out of hatred." I know this is hard to hear, but if we are going to make real efforts not to perpetuate oppressive practices, we have to take a long, serious look at how we privileged people, and not just whites, but all of us, perpetuate racism unknowingly. And

we can't fall into the trap of thinking that our good intentions protect us from being complicit with oppressive practices.

This is true in society in general, and it is also true in medicine. By participating in medical culture, which we necessarily do by being medical students, by going along with the status quo, we are already actively perpetuating an inherently racist culture. The men who are often referred to as 'the father of psychiatry' and 'the father of obstetrics and gynecology' both performed experiments on slaves. We know about the Tuskegee syphilis experiments. Medicine has a long history of racism in this country. In fact, one of the necessary steps we must take if we want to eradicate racism from medicine is to come to terms with medicine's long association with slavery and the legacies of slavery. (That, however, is another thesis project.) However, I do want to address what seems to be a common response to suggestions that our world today has anything to do with slavery or any other institution or event from the "past". Here's a quote from Michael Lucey, from a lecture in which he was discussing Pierre Bordieu's work:

"The practical set of habits we move through are a product of history- they ensure an active presence of past experiences, and ensure continuity over time of "correct" practices, more effectively than rules could." (Lucey)

I've emphasized that every experience colors our way of perceiving the world. But I don't mean that our experiences are limited to those which we personally undergo. Our experience comprises the sum of our cultural history, regardless of whether we were present or even alive. Just because I wasn't there doesn't mean it hasn't left a trace. Now, this doesn't mean that we are all doomed to be perpetrators of all the evil that has ever taken place. We can control how we perceive the world and what we chose to pass on. Gramsci tells us that deposited in each of us, without an inventory, is an infinity of experiential traces. If we want to gain access to the perceptive lens that these traces form, what we need to do is to establish an inventory.

I'm going to return now to our first classroom scenario, when the guest lecturer has said that county patients can't be trusted, and the regular teacher and the students are all silent. I want to draw a distinction between the role of the students and the role of the teachers. The teachers do not necessarily have a greater or lesser role in this situation, but their role is distinct from that of the students because they represent the institution. Here's another quote from Patricia Williams:

"The respect accorded any teacher is only in small-- if essential -- part attributable to the knowledge inside the teacher's head. What makes one a teacher is the force lent to one's words by the collective power of institutional convention." (Williams, 1995, p. 39)

She specifies, the force lent to one's words. I would amend this to, "the force lent to one's words and to one's silences".

The teacher, no matter how casual the classroom setting, no matter how we relate to him personally, or know that he means well, still represents and embodies the institution. And no matter how hard I may try, I cannot ignore or forget that he *does* represent the institution, and that he carries the authority of the institution with him. In his book "Orientalism", Edward Said discusses authority. This passage, I think, is particularly appropriate for what I'm talking about.

"There is nothing mysterious or natural about authority. It is formed, irradiated, disseminated; it is instrumental, it is persuasive; it has status, it establishes canons of taste and value; it is virtually indistinguishable from certain ideas it dignifies as true, and from traditions, perceptions, and judgments it forms, transmits, reproduces. Above all, authority can, indeed must, be analyzed." (Said, p. 19)

Now, of course by analyzing authority I don't mean trying to tear it down or eliminate it. I mean we can pay attention to the hidden *and* overt ways that teachers' and doctors' authority acts, and hopefully put this understanding to constructive use.

In the recent JMP newsletter, there is a report of Alison Kneisl's survey. One of her findings was that JMP students believe they learn from their teachers/role models

about doctor-patient interactions. So this isn't some subtle, hidden effect. We actively look to our instructors as role models, to learn how to be doctors.

* When one teacher has made a bigoted comment, and another teacher refuses to intervene, we're being taught that in medical culture, it is more acceptable to allow the perpetuation of bigotry than it is to disagree with a colleague. (I find this incredibly sad.) We are also learning that bigotry won't get in the way of anyone's becoming a well-respected doctor who is called upon to teach medical students and to serve as a role model for them. In this situation, we find ourselves in the midst of a reinscription of medical culture. And we, the students, in our complicitous silence, are drawn into the web; we are participating in its production. As Patricia Williams sums up so beautifully,:

"If, moreover, all our colleagues pursue the same path (insult, embarrassed pause, the world keeps on moving as though nothing has happened), then we have collectively created that peculiar institutional silence known as a moral vacuum." (Williams, 1995, p. 40)

Now I'll go back and tell you how the story ended. One student did muster up the courage to say something. She engaged the guest teacher in a discussion of his view of county patients, and it actually worked out well. Our guest eventually agreed that what he had said was unfair. He was not insulted at having been questioned, and he'll most likely be back to teach next year.

(That this scenario ended positively is a credit both to the student who spoke up and to the guest teacher. We learned that our guest was not as fragile as we had feared. In hesitating to confront this man, we had been assuming that he was protected by a bubble of an authoritarian shell, and that any challenge to him would burst that fragile armor.)

I want to make one last point about the two scenarios I've presented. In both situations, we have doctors who express bigoted thoughts or actions. The main difference is that in the first case, that doctor is in our presence- he speaks his bigoted thoughts directly to us. In the second case, the doctor is imaginary for those of us hearing the

story. Notice the striking difference in the way we react to these two situations. When the doctor is in our presence, the students hesitate to speak, and the teacher remains silent. But when the doctor is only hypothetical, brought to us through the story of a fellow student, we eagerly criticize his bigoted behaviors. And, most notably, the teacher joins in the criticism too.

Contributing to our reluctance to question our guest teachers is our understanding of them as experts in their fields. What happens when we designate some people "experts"? We are setting up a hierarchy of knowledge, saying that because a person has been doing what they have been doing a lot, and for a long time, that their knowledge is to be privileged over others'. The cardiologist who has been practicing for twenty years becomes the authoritative source of our knowledge on heart disease. But in designating this person the expert, we cut off, deny, chose not to see the context of this person's knowledge, and the limitations of that knowledge. Privileging expert knowledge over all else means not having to pay attention to the context or the ramifications of that knowledge. This man may have been practicing all of his twenty years on a very specific patient population. In the case of most of the guest instructors at JMP, they have most likely been treating a mostly white, educated, and upper class patient population. They have been reinforcing their own views, expectations, and ideas over those twenty years in that particular setting. Why do we assume that what they have to offer us is definitive? Why are they necessarily the expert, rather that simply another voice, someone who has a wealth of experience to share with us, but a particular kind of experience that may not be applicable in other situations, with other patient populations?

For example, we recently had an instructor talk to us about Reiter's Syndrome. He said that "most cases of Reiters are post-dysenteric, from people returning from vacations in Mexico. You'll rarely see chlamydia-associated Reiter's." "Really?", I asked. "This summer, I worked at San Francisco General Hospital, and the impression I got was that there, they see mostly the STD-associated form." "That's true- at the county hospital, they

see a lot more STDs, and probably not very many people coming back from vacations in Mexico." How many times are we not finding this out, are we not asking for contextualization? How much does our thinking of these guest instructors as "experts" preclude us from asking these questions? This is an example of how we are only receiving a limited subset of medical knowledge, and how this, plus our fear of questioning these experts on their topics, can cause us to give our future patients worse or inadequate care, by not knowing about conditions that we will see in other settings.

VII. Diary of a Third Year Medical Student

Thesis Presentation/Chair #3

At the end of our third and final year in the JMP, students give oral presentations of their thesis work. For months I had assumed that I would speak about Asian AIDS Project and their outreach methods- it was the safe, non-threatening part of my thesis work, and I didn't have the strength, or the will, anymore, to take any risks. But in an unexpected last minute burst of intrepidity, I decide three days before I am scheduled to speak that I will instead present my ideas about medical culture and the ways we unknowingly reproduce oppressive practices in medicine. This is my real project, I think, this is what I want to say out loud to the JMP community.

In planning my talk, I take great care to word my ideas in general, gentle terms. I know that there's a tendency for people to take criticism personally. I know that in the past people have complained about my "tone". I decide to spend a good portion of the talk reassuring the audience that I do not intend this to be critical or judgmental of the actions of individuals, but rather of the way all of us participate in medical culture. By the time I have written this talk, it seems so watered down, so full of hand-holding, that it seems not risky at all. It is carefully worded, well thought-out, makes my points clearly and simply, and doesn't mention individuals at all. In its final form, I cannot imagine how anyone could possibly take exception to any of what I say.

After the talk, several of my classmates rush up to congratulate me. They offer me hugs and kisses and emotional thanks for saying things that needed to be said.

"You're such a radical", my best friend whispers. Quite a few students, in my class and in the first and second years, as well as several faculty members, seem to have been emotionally moved by my presentation, and let me know that they appreciated my words. I go home elated, and get my first night of restful sleep in weeks.

The next morning, several students in the first year class stop me to tell me how much they liked my talk. A couple of them give me hugs. One wrote me a card to say thank you.

Other students, though, have stopped speaking to me. One even starts to cry every time I try to talk to her. I no longer know what to expect from my fellow students. Some still hug me everytime they see me; others make no effort to hide their disdain.

A conversation with a first year student, though, gives me hope as I leave the JMP. He told me that the ideas in my talk have influenced their behavior. In their medical interviewing course, with the very same Doctor, they have started noticing when they are sliding down the slippery slope to self-congratulations at the expense of critical thinking. Rather than just tell stories about bad doctors they have encountered, he tells me, they are now reminding themselves that they too are prone to behaving oppressively. They take the time to ask what might lead them to behave as these bad doctors have, and what they can do to change that behavior.

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