The Uninsured and the Politics of Containment in U.S. Health Care

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State-provided health insurance has now spread throughout much of the industrialized world. The United States is a particular exception to this trend. The U.S. uninsured represents one-sixth of its population. The uninsured exemplify those on the margins of the U.S. health care system. Based on qualitative research with 215 chronically ill, uninsured ethnic minorities, I argue that the U.S. system fosters an organized approach of containment toward the uninsured that not only marginalizes them but it keeps the problem of the uninsured in check by discouraging people from using health care services. Respondents viewed the treatment they received as an assault on their dignity and experienced discrimination, depersonalization, and disenfranchisement. They avoided using the health care system whenever possible despite chronic, life-threatening illnesses. I conclude that the uninsured, as a problem of the state, lies at its very heart, with implications for the health and well-being of the uninsured as well as for the governmental systems that attempt to manage and contain them.

Key Words: African Americans; chronic illness; Latinos; Uninsured
How the state manages its margins has been a perennial question in anthropology. Das and Poole (2004:4) suggested that margins are a necessary entailment of the state; that is, states have boundaries, for example, between center and periphery, public and private, and legal and illegal. By examining the margins of health care systems, we can better understand how governance shapes and facilitates a process of exclusion for some, with deleterious effects on people’s health and well-being. Governmentality, according to Foucault (1991), is “the ‘conduct of conduct,’” a form of activity aiming to shape, guide, or affect people’s conduct. Health care in the industrialized world has been increasingly regulated by the state, and among those forms of regulation, one in particular stands out: the extension of national health coverage to citizens. Social (health) insurance can be seen as an inclusive technique of government and a regulatory device, especially in Europe (O’Malley 1992; Rose 1996). Rose (1996:152) observed that health insurance creates connections between public norms and the fate of individuals in their personal lives, including their economic well-being.

Lack of health insurance raises questions about marginalization and what the effects of marginalization are for the individuals involved, for the health care system, and for the overall system of governance. Currently, forty-eight million people in the United States, or one-sixth of the population, have no health insurance at any given time (Collins et al. 2006). The number of people without insurance rises every year. The uninsured in the United States are systematically less likely than the insured to receive effective, safe, and timely care (Institute of Medicine 2002). Following Foucault (1973), marginality reflects the biopolitical division between those whose lives are managed with the goal of enhancement and those whose lives are judged as less worthy and who are allowed to die.

Racialization within health care is one example of the marginalization of certain sectors of the population in the United States. Overt racism in the United States has been largely replaced by various forms of racialization that are embedded in U.S. society’s institutions and approaches to various groups of people on the basis of race, social class, and gender (Mullings 2005). Ethnic minorities are disproportionately represented in the ranks of the uninsured: 19 percent of African Americans are without health insurance and 35 percent of Latinos have no health insurance, compared with 10 percent of white Americans (Robert Wood Johnson 2004).
means that Latinos are three times as likely to be uninsured than non-Latino whites, while African Americans are twice as likely to be uninsured as whites.

Differences in life expectations and health status for ethnic minorities, when compared with whites, are dramatic. For example, life expectancy of white men is 6.6 years longer than that of African American men, and the life expectancy of white women is 4.9 years longer than that of African American women (Statistical Abstract of the United States 2003). Rates of death from heart disease are about 30 percent higher among African Americans compared with whites, while disparities in the prevalence of diabetes are even greater, with prevalence rates 70 percent higher for African Americans than whites and almost 100 percent higher for Latinos (U.S. Department of Health and Human Services 2002).

Moreover, the United States has a two-tier hierarchy of health care: the private sector, which includes private practices and health maintenance organizations for those who have health insurance, a system used predominantly by the middle and upper classes, and the public sector, for those who are eligible for government-funded health insurance such as Medicaid or who have no health insurance, a system predominantly used by those who are poor. Health care in the public sector has grown out of nineteenth-century charity care (Schroeder 1996). Public-sector health care is widely acknowledged to be underfunded and heavily overburdened by the large population it seeks to serve and is further undermined by steady and persistent governmental funding cutbacks at all levels of this system (Davis 1997; Horton et al. 2001), a further reflection of biopolitical differentiation of management approaches for different population groups. African Americans, Latinos, and other racial/ethnic groups are disproportionately lower in income compared with white, non-Hispanics and are disproportionately treated in the public-sector of the health care system.

In this article, I examine how the state further marginalizes uninsured, chronically ill African Americans and Latinos through an effort to contain the uninsured and diminish the extent of the problem. Emphasis is placed on managing and normalizing health care differentially for those with health insurance and those without it, even if the ultimate cost to the state may be greater by doing so, in terms of both human life and economics. In public-sector health care, specific policies shape the bureaucracies in which care
is delivered and the very nature of that care. I argue that these policies work to foster an organized approach to contain the uninsured—an approach that trickles down into specific encounters and affects how those who are uninsured respond. This overall approach toward the uninsured not only serves to further marginalize them, it also has the effect of keeping the issue of the uninsured in check by discouraging people from using much needed health care services. I explore this situation through a qualitative study of uninsured, chronically ill people who are members of ethnic minority groups.

HEALTH INSURANCE FROM A GLOBAL PERSPECTIVE

The concept of social health insurance—that is, health care paid for by the state—is deeply ingrained in the fabric of health care systems in Western Europe, and is an organizing principle in numerous countries where social health insurance is seen as a way of life (Saltman 2004). Social health insurance reflects core values that are embedded in the very heart of how these societies understand themselves (Saltman 1997). As such, they are tied to national culture and grounded in the historically generated principles of collective responsibility and social solidarity (Saltman 2004).

State-provided health insurance has now spread throughout much of the industrialized world, including Central Europe (Saltman 2004) and Japan (Motomatsu and Hirata 2002). The proportion of persons covered by health insurance varies, however. For example, even in the seven Western European nation-states that pioneered social health insurance, not everyone is covered by the respective systems: the proportion of persons covered ranges from 63 percent to 100 percent, depending on the nation (Saltman 2004). Nevertheless, the right to health care is recognized in international law and is guaranteed in the constitutions of many nations (Jost 2003; Scott 2004). The United Nations’ key precepts of the right to health include availability, accessibility, acceptability, and quality of services (United Nations 2000). To the extent that care is rationed globally, it is usually done on the basis of clinical need, not ability to pay (Keen, Light, and May 2001; Dixon and Mossialos 2002).

Despite the widespread expansion of health insurance in industrialized nations, not all nation-states have followed this trend,
especially in Southeast Asia, South America, and the United States (Saltman 2004). The United States is a particular exception, given its acknowledgment as one of the wealthiest nations globally. The United States is the only western industrialized nation that fails to provide universal coverage and the only nation where health care for the majority of the population is financed by for-profit, minimally regulated private insurance companies—arrangements that leave one-sixth of the population uninsured (Quadagno 2004). In an era of rapidly rising health care costs, having health insurance has not only become highly desirable, it is widely viewed as a necessity of daily life for physical, social, and economic well-being.

Questions about the management of those on the margins of the state have implications for the general health and welfare of nation-states that have populations not covered by national health insurance. Citizenship may be one determinant of health insurance. While citizenship has been generally thought of in anthropology as an ideology of equality, entailing certain rights (Holston and Appadurai 1999), Ong (1996) has suggested a more complex way of considering citizenship: as a “cultural process of subject-ification, in the Foucauldian sense of self-making and being-made by power relations that produce consent through schemes of surveillance, discipline, control and administration” (737–738). For Ong, cultural citizenship refers to cultural practices and beliefs produced out of negotiating ambivalent and contested relations within the state and its hegemonic forms that establish the criteria of belonging within a national population and territory.

Some form of social health insurance has become a marker of citizenship in much of the industrialized world. In European countries, health insurance may be extended to citizens and guest workers but exclude illegal or undocumented immigrants, which is a considerable number of people. It is estimated that between 120,000 to 500,000 people enter the European Union (EU) by irregular means annually (International Organisation of Migration 2003). Germany, for example, is host to 36 percent of the EU’s foreign residents (Martin 2003:44). The number of undocumented migrants in Germany is estimated to be 150,000 to 1.5 million people (Migration News 2003; Martin 2003:49). Although in theory undocumented migrants can obtain medical care in Germany, residing there without a valid permit or visa is a crime that is enforced, including criminalizing assistance to them; undocumented persons are thus
excluded from the use of health care resources (Scott 2004). In Great Britain, recent changes to National Health Service regulations that make legal residence of a specified duration a condition of care except for emergencies have the effect of excluding undocumented migrants (Scott 2004).

Whereas in Europe, cultural citizenship may be extended to guest workers who are incorporated into regulatory regimes while those who are undocumented are excluded, the picture is more complex in the United States, where foreign-born, non-elderly adults are twice as likely to be without health insurance as their native-born counterparts (Pol, Adidam, and Pol 2002), and non-citizens who have been in the United States for five years or less are four times as likely to not have job-based coverage as U.S.-born workers (Ponce, Nordyke, and Hirota 2005). In the state of California, immigrants make up 29 percent of employees in the workforce but 54 percent of its uninsured are working adults (Current Population Survey 2000), which has been attributed to citizenship status (Carrasquillo, Carrasquillo, and Shea 2000; Ku and Matani 2001). Undocumented, or illegal, immigrants are the least likely to have health insurance or access to health care (Chavez, Flores, and Lopez-Garza 1992).

Although citizenship and immigration status are the primary determinants of health insurance status in Western Europe, there are additional determinants of that status in the United States. Most uninsured persons in the United States are poor or near poor. They cannot afford to purchase private health insurance and they do not qualify for state-funded health insurance, which is primarily earmarked for jobless single parents who are raising children, for persons who fit the state’s criteria for disability, and for those who are older than 65 years. Many employers do not offer health insurance to their workers, and thus another group of uninsured is composed of people who work but have no health insurance through their employment and cannot afford to purchase private health insurance on their own. These observations suggest that the parameters of cultural citizenship may be more narrowly defined in the United States since one-sixth of the population can be considered disenfranchised on the basis of health insurance alone.

The effects of being uninsured are far-reaching in the United States. The risk of premature death is higher in the uninsured than in those who are insured: uninsured non-elderly adults are 20 percent to 50 percent as likely to die than those with health coverage
The Institute of Medicine (2002) estimate of 18,000 annual deaths of uninsured 25-to 64-year-old adults makes the lack of health insurance the sixth-leading cause of death among people aged 25 to 64 years (Davis 2003). Reducing mortality by 5 percent to 15 percent could be expected if the uninsured were to gain continuous health coverage (Kaiser Commission 2003).

Lack of treatment for chronic and disabling illness particularly exemplifies the human cost of lack of health insurance. Compared to persons who are insured, uninsured people who are chronically ill have many more health crises (Becker 2001). They are more likely to be diagnosed in the late stages of cancer, and those who have been hospitalized for heart attacks are over 25 percent as likely to die while in the hospital (Hadley 2003). The uninsured are more likely to delay needed care (Becker 2004). Half of uninsured people report being temporarily disabled by their health problem, and 15 percent to 20 percent have a long-term disability (Hadley 2003). People who lack access to health care services may accrue a pent-up demand for services, and when they become eligible for state-funded services, they may be more ill and receive services in a more expensive venue: lack of health insurance may thus result in greater long-term health care costs because illnesses are diagnosed later and people are sicker when they do receive care (Pol et al. 2002).

In the face of these sequelae of being uninsured, governmental techniques to manage the uninsured and normalize the health care system have been to contain the uninsured while, at the same time, creating governmental distance from the problem. Rose (1996:155) maintains that in the current era of “advanced liberalism,” or neoliberalism, techniques of government such as this create a distance between the decisions of formal political institutions and other social actors; conceive of them as subjects of responsibility, autonomy, and choice; and shape and utilize their freedom. In the United States, this approach has led the government to propose a model referred to as “health savings accounts,” which would further distance the government from a proposed form of national health insurance by individualizing the model and putting the responsibility for effective management on the users. Most people who are uninsured, however, lack the economic resources to pay even modest amounts for these health insurance accounts from their incomes. As we will see, people in this study feel they have little recourse and turn to public-sector health care when they are ill.
METHODS

I conducted an interview study with chronically ill ethnic minorities who are uninsured. I focused on chronically ill people because of their need for continuity of care for their illnesses. The total sample of persons who are completely uninsured is 215:136 African Americans, 70 Latinos, 7 Khmer Americans, and 2 Filipino Americans. The age range was 22 to 72 years, with a mean age of 47. Respondents were recruited through 16 health and social services sites, including county hospitals, community health clinics, and community service agencies in two urban counties, using flyers, referrals from clinic and community workers, and introduction of interviewers to prospective respondents. We sampled a range of illness severity, from mild to severe, and most people reported they were seriously ill.

Four interviewers interviewed respondents one to three times over a one-year period, usually at home or in the project office. Over two-thirds of the sample was interviewed more than once. Tape-recorded ethnographic interviews were one to two hours long and were semistructured with many open-ended questions. Interviews focused on illness experiences, self-care practices, use of and access to health care, and economic and living situations. Respondents’ interpretations of their experiences were emphasized. Interviews were transcribed verbatim. Respondents were interviewed in their language of choice by interviewers who were members of the same ethnic group. African Americans were interviewed in English. Sixty Latinos were interviewed in Spanish; ten were interviewed in English. Khmer Americans were interviewed in Khmer and Filipino Americans were interviewed in Tagalog. Data collected in languages other than English were translated by the interviewer and transcribed into English.

Data were divided by ethnic group, analyzed separately, and then compared across groups. A case-by-case narrative analysis was conducted (Becker 1997). The analysis included a close reading for (1) repetition of specific words, phrases, and general thought patterns; (2) the structure of the overall story; and (3) the topics that dominated respondents’ reports as well as topics that were not raised at all (Kaufman 1986). Although cultural differences were found between and within groups, the emphasis in this article is on the experience of being uninsured, which demonstrated great consistency across groups.
REACTION TO THE UNWIELDY BUREAUCRACY

People reacted with outrage and disillusionment to the treatment they received in large health care bureaucracies. In contrast, there were relatively few complaints about small community clinics, but a key limitation of those clinics was the inability to provide anything beyond the most basic health care, necessitating that sooner or later most people had to deal with large and unwieldy bureaucracies.

The necessity of dealing with the health care bureaucracy interferes with medical care right from the start, before people even see a health professional, and initiates what people almost invariably report is an unsatisfactory experience. Within the overall bureaucratic structure, two systems are entwined: the payment system, and the medical training system, which includes the management of large numbers of patients. Both systems are set up to maximize surveillance and efficiency, two primary components of containment.

RATIONING, THE NEWLY UNINSURED, AND THE BENEFITS OF INSURANCE

Not having health insurance posed a major barrier for everyone in the study. Those who were newly uninsured reacted with shock and alarm to refusals to see them on the part of private medical practices. They were unaccustomed to health care being rationed on the basis of ability to pay or the perception that a person might not pay their bill. For example, an African American woman who had had open-heart surgery and had high blood pressure reported: “During December it [blood pressure] was sky-rocketing. I couldn’t see my cardiologist because I didn’t have insurance so that was stressful for me. Here I am—experiencing panic attacks, palpitations, and all these things, and twice they turned me down to see my regular cardiologist that I have been seeing for the last ten years because of no insurance. I was having a headache, it was like a dull headache that would not go away, and just nervous because I had open-heart surgery 20 years ago, and thought, ‘What is going to happen if I can’t control the blood pressure?’ I had feelings of doom. I had made this appointment three months in advance.”
Frightened and anxious, she could not find an acceptable alternative to seeing her cardiologist. Ultimately, she received no care: ‘I felt like, ‘Oh, my God, I am going to die.’ I was having problems, and they didn’t care. I cried because I had been a patient for so many years with this doctor, and all of a sudden I didn’t have insurance: ‘Sorry, we can’t service you.’ So I had to find other means. They told me I could have gone to the Emergency Room. I didn’t go because I felt humiliated, and I didn’t want to waste the time to go there.’’

Although people usually acknowledged that the quality of medical care was good, they were affronted by the overall bureaucratic approach, the impersonal, sometimes brusque, treatment they received from clerks. For example, an African American woman, newly uninsured and unaccustomed to receiving care in the public-sector system, reported: ‘I went [to the county hospital] with my husband once. He had such a bad experience that it turned me off. That hospital is famous for having very good doctors but the administration side of it is so bad. You wait so long. They are not courteous. They treat you a little different when you don’t have insurance. Those are the things that turned me off. I wasn’t used to it.’’

Rationing is managed in specific ways in public-sector health care. People do not usually meet with an outright refusal. Instead, they are referred to emergency services if they cannot wait weeks for an appointment. Once seen, they may be refused medication to manage the health condition, however. An African American woman reported, ‘I spent eight hours to find out that my blood pressure was high, and there was nothing they could do about it. They told me to go home and rest because I was not on any types of meds, and they were not going to prescribe any because I couldn’t pay for them.’’

There is an implicit hierarchy in public-sector health care between those who have insurance, even government-funded insurance, and those who have none. In other research, I have collected large quantities of data from people who receive Medicaid (government-subsidized health insurance) and who are unhappy with the very same system. But from the standpoint of those who are uninsured, there is a difference. An African American woman said, ‘If someone has Medicaid, you get better service, but when you have no insurance, it is really different. You can see the atmosphere and how it goes.’’
Asked, “Tell me the difference between having insurance and not having insurance,” she said: “They are quicker to serve you. I was just bitten by a dog. When I called the ambulance and told them I had insurance, I wasn’t taken to [county hospital], they didn’t even mention it. They took me to a private hospital and treated me right away. Otherwise I would have stayed in a long line at [county hospital], and I would have been sitting and waiting and waiting. When I had insurance, I got service.” This woman concluded, “It feels great to be on Medicaid. Even though the state is paying for it, I get better service and more care. After I got Medicaid I decided to switch to a private physician.”

BUREAUCRATIC REGULATION AND SURVEILLANCE

The question of who pays for care shapes the process right from the start. In a typical response to the question, “Has being uninsured been an issue when you seek health care?,” an African American woman said: “Yes, because that is the first question that comes up: ‘How are you going to pay?’ It is always an issue.” People perceived this initial question negatively. Another woman explained, “Even if I go to a doctor, even before I am seen, they are going to send me through this rigamarole: ‘Fill out this, have you applied for Medicaid? yardy, yardy, yardy.’ Then you fill it out, then you are denied, then they bill you. This is at the county hospital, because this is the place to go if you don’t have insurance.” She concluded, “But then you are denied and the services stop right there. I am having problems with my breast. They examine my breast and don’t find anything. They will say you need to schedule to come back and get a mammogram. In the interim my Medicaid has been denied; then I am going to have to pay for that mammogram, which I am sure I can’t afford.”

The surveillance system in county hospitals was relentless. People viewed these systems as nonsensical and completely inefficient. For example, an African American man said: “Another thing about [county hospital] that is really archaic is that almost every time you go there you have to get a new card. Their ID cards are only for seven days, and so you have to go and do that before you do anything else, stand in line and get a new ID card first, which is ridiculous, but that is the system.”

The timing of patient appointments is a major issue for recipients of public-sector health care. Respondents were usually told to show
up at 8:30 a.m. or at 1:00 p.m. and then they waited half a day to be seen. The system is set up for the convenience of the staff, to maximize their efficiency. Long waits provoked people, however, and were seen by the recipients of care as a prime example of the inefficiency of the system. For example, an African American woman said: ‘I asked this nurse one time, Why did you give me a 9:00 appointment if I can’t see the doctor til 11:00? I could be doing something else for those two hours.’ She said, ‘That is just how we do it.’"

People reported finding the entire process exhausting. For example, an African American man said: ‘Just the whole framework of it—you wait six weeks before somebody sees you. Then you sit several hours. Finally, when somebody sees you, you’re so exhausted, you don’t even want to talk to them anymore. You forget what you’re supposed to ask them.’

Getting beyond basic health care to gain access to specialists was problematic and was a common complaint. For example, an African American man said: ‘It’s hard getting access to specialists. The way it’s structured right now, you have to beg for everything. It takes six weeks to see the doctor, then you gotta wait another six weeks to go to this specialist. And there’s zero interest in you.’

People observed cutbacks to the system going on around them and predicted what that would mean for their own health care. For example, an African American man said: ‘The County made some major budget cutbacks. They closed two county clinics, just closed them. That means that people are going to other clinics and going to have to wait in line.’

Two-thirds of this sample reported feeling discriminated against because of their lack of insurance. African Americans most often reported feeling discriminated against: ‘I think if you’re uninsured you get put on the back-burner. You get elevated or skyrocketing prices. Or if it’s the same price, why can’t you get a lower rate if you’re paying out-of-pocket?’ Feeling discriminated against was often entwined with communication problems for Latinos: ‘There is a lot of discrimination because I’m Latino and because I don’t have insurance. They take a long time before they ask for a translator. They see other patients before me. The ones who get there after me and speak English, they see them first.’ Some Latinos felt the care they received was of a different quality: ‘They don’t give you the same care in comparison to someone that speaks English.’

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LACK OF RESPECT AND DEPERSONALIZATION

Medical bureaucracy in public-sector health care often involved knee-jerk protocols, and consequently, people experienced a lack of respect. For example, an African American woman indignantly reported: “When I had the HMO, I was treated just like everybody else. Here I have felt disrespected, talked down to. I was having symptoms [of high blood pressure], and they asked was I pregnant? I was 50 years old! Then they asked, ‘Have you ever had an abortion?’ No! My tubes are tied and that has nothing to do with me being nauseated, me being dizzy, me being diagnosed with high blood pressure. What does that have to do with it? This really angered me, and then I had to sit in a waiting room for 5–6 hours.”

When public hospitals are teaching hospitals with an agenda to train health professionals, an additional feature of the medical bureaucracy comes into play, as medical students and residents rotate regularly for training purposes. In health care encounters people often felt depersonalized or treated like specimens. For example, an African American woman said: “First, the intern comes in and then the doctor comes in afterward and checks what they’ve done and then re-does everything to make sure they were accurate. Then the doctor will say to the intern, ‘If you’re looking at her, what is it that you see that you’ll notice right off?’” He said, “Look there, there’s a little thing right here. Her blood pressure’s up and that vein is sticking out, and you can see a pulse.”

Other people reported on what they viewed as assembly-line care. An African American woman reported: “It is like an assembly line. I do not think that they personalize care. I don’t want to become a file number somewhere.”

WORKING THE SYSTEM

Some people tried to work with the system, to make it more responsive to their needs. But no one reported that they were able to do this with ease. People invariably viewed the system as an obstacle course that they had to run. In a typical example, an African American man said: “That broke me down. I had to deal with the system to the best of my ability. I dealt with it just by trying to work it the best I could. Basically I did work it, it was just miserable to work with. I can see how people have a difficult time dealing with
systems, especially big city medical systems. You have to put out so much energy just to get the minimum that some people just don’t bother. Quite frankly, it is only the people that have learned to live with the system, know the little things, play up to all the characters so they get taken care of. Those are the people that survive in these systems.” He concluded, “I have to tell you, you have to con your way with people. You have to work it, and everybody can’t do it. I did work it, but it was still miserable. I worked it with everybody in that clinic, and it got very frustrating, and it just wasn’t worth it.”

Some people attempted to develop strategies for working with the system. For example, an African American woman said: “Because of my background in the health care field, I know how systems go, from the intake process from the time you arrive to seeing the doctor. So when I go to [county hospital] I have to figure out some strategic way to expedite myself through this process because I am not going to sit over there in that waiting room 3–4 hours like these women are, ‘cause they don’t know how to get through the system.”

People reported their frustration and their need to monitor themselves so that they would not take their frustration out on health professionals, thus making the receipt of care more difficult. For example, an African American man said: “At times you get frustrated and pissed off. You don’t want to get an attitude because then you won’t have a doctor. No one. I have been transferred around already, and because of that I am not trying to tell the doctor how to do their job, but I do appreciate somebody listening to me.”

AVOIDING THE HEALTH CARE SYSTEM

Most people gave up, at least for a while. Approximately 80 percent of those who used county hospitals for their health care (the majority of the sample) went through months in which they avoided the system, and at least half of those persons perpetually tried to avoid the system except in an acute emergency when they felt forced to seek care. People who used county hospitals resorted to delay or avoidance of the system altogether because they found dealing with the system so demoralizing. Some who used the system without avoidance reported doing so because their fear of dying or having their health significantly worsen was greater than their distaste for the system.
An additional deterrent to seeking care was lack of continuity in health care, in particular, a tendency to not be given the same physician twice. For example, an African American man reported on the lack of continuity of care: “That is another thing that is a problem, I never have the same doctor twice. I go to different doctors. I noticed that each time I went it was always someone different. Now I avoid them. I avoid going to the doctor as much as possible.”

People gave many reasons for not using public-sector health care. For example, a Latina who had degenerative arthritis commented on the ultimate deterrent to seeking care—the cost. She said: “Basically what stops me [from seeking care] is my financial situation because unfortunately I don’t have the funds to deal with a cost of this type. I don’t earn a lot of money, and he [husband] is the only one that works. I would like to help him [to earn money] but I can’t because I can’t with my legs.”

Even in an emergency people avoided using the health care system. For example, a Latina who fell on the street reported: “I didn’t want to go [seek health care]. People were saying, ‘You want us to call the Emergency?’ I said, ‘No, no, please don’t call anybody. I don’t have insurance.’ So I got up to go home. And they were like, ‘You are going to drive like that?’ I went to a chiropractor I used to work for, and she wasn’t there. I wanted an x-ray because I felt something was not right because the pain was so huge. I could not believe the pain. Although she wasn’t there, someone helped me get crutches.”

People frequently reported indecision about seeking care and an internal debate with themselves about whether to seek care went on interminably. For example, another Latina reported: “Since I’ve been uninsured, there are times when I have trouble breathing, and I’m not really sure what’s going on, and I think that if it gets worse during the night I’m going to go ahead [and seek care].” Ultimately, however, she did not. Instead, her prescription for hypertension medication ran out. She described what happened next: “[Symptom] was building up and building up until the end of the day. It got so bad, it got worse, so I called my friend and I told her I was having problems.” But she continued to postpone seeking care and tried to manage the symptoms: “What I try to do is see if I can control it. You know, see what it’s going to do eventually. It is my heart muscle—it is just going to wear out. It is either that or a stroke.”

Respondents analyzed how this system affected them and concluded it was an assault on their dignity. For example, an African

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American woman, when asked, “Do you think you are treated in a particular way because you are uninsured?,” responded: “Sure. I don’t think it is solely by the people who treat you but I think it is by the people that regulate them. You have to go through so much protocol, paper work, little things that you wouldn’t have to if you had health coverage or if you could go to your own doctor. I can understand why a lot of people don’t go to the doctor when they have to because it is almost as though they take your dignity from you.”

THE BREAKDOWN OF CONTAINMENT AS A STRATEGY OF GOVERNANCE

Examining how nation-states attempt to manage the margins of society through biopolitics can reveal how the margins may actually be at the center rather than the periphery. This way of viewing health care systems can provide a unique lens through which to understand specific dilemmas in health care delivery. When marginality is identified, it is most often viewed in relation to the spatial margins of societies rather than at its center (Das and Poole 2004:33). In the case of the uninsured in the United States, however, we see how the uninsured as a problem of the state lies at its very heart. Neoliberal governance is thus faced with the task of attempting to make the problem of the uninsured appear obscure and much smaller than it is. Rose (1996) noted that one way in which this is done is through transforming health insurance from a principle of social solidarity into the privatization of risk management. Staying healthy thus becomes a private obligation, and the vehicles that help to maintain health, such as health insurance, also become the responsibility of the individual. Hence, neoliberal governance develops schemes that would require individual subscription such as privatized health savings accounts in the United States, which people who are poor cannot afford.

The primary way in which this effort is conducted in the United States is through policies that seek to contain the problem, both directly and indirectly. If the problem is acknowledged to be as big as it actually is, with its real-life consequences for health and well-being, neoliberal governance will be unable to proceed with its goal of further reducing government subsidization of public-sector health care. Its proposals for health care coverage that are
predicated on individual responsibility and are distanced from the
government will be to no avail.

One critical, yet largely hidden, facet of this dilemma is how the
management of the problem facilitates racialization. The numbers
of uninsured are disproportionately composed of ethnic minorities
who are poor and who receive their health care in the public-sector
system, where they experience discrimination. Ong’s (1996) sugges-
tion, that cultural citizenship is connected to various regulatory
regimes, is borne out by this research. The criteria of belonging in
the United States differ from other industrialized nation-states.
Legal citizenship alone is insufficient to “belong.” What is needed
for cultural citizenship is being a member of the white majority and
the economic means to purchase health insurance. (Uninsured
whites who are poor or have modest means also lack cultural
citizenship.)

When the state attempts to contain rather than to ameliorate a
problem such as that of the uninsured, it may initially appear to
be effective. The United States maintains a highly bureaucratized
policy of containment within the health care system that is intended
to order and control the problem. Interrogating the politics of con-
tainment surrounding the uninsured illustrates how the state man-
ages its margins through a specific form of order. In the United
States, the state works to contain the marginality posed by so many
uninsured people through a highly ordered, extraordinarily
bureaucratic, and time-consuming system. Strathern (2000) refers
to such systems as “audit cultures,” in which accountability is a
central feature of the bureaucratic approach. Although all health
bureaucracies in general—both public and private—are ordered,
with the audit as central, the emphasis in this particular system is
on containment of marginality, namely those who are uninsured.

Efforts to regulate and normalize the delivery of health care go
hand in hand with efforts to contain and exclude the uninsured
from public-sector health care. Differences and similarities between
those having state-funded health insurance versus those having no
insurance at all were revealed in this study. The newly uninsured,
in particular, were shocked and chagrined by the impersonal,
highly bureaucratized system. Although surveillance of both
state-insured and uninsured is a key parameter of public-sector
health care, those who receive state-funded insurance experience
some freedom of choice. In contrast, those who have no health
insurance view themselves as having little or no choice in the
struggle to find health care. Not only do they view the scrutiny they are subject to negatively, they view their treatment as being regulated and contained.

Efforts to contain the problem of the uninsured are likely to falter seriously, if not to fail, in the long-term. This is especially true when the capacity of the system is strained by growing numbers of people who must rely on it, as is occurring currently. The public-sector health care system in the United States was never designed to manage such great numbers, and is increasingly hampered by underfunding and budgetary reductions (Schroeder 1996). As the numbers of uninsured people grow, it continues to provide services to ever-growing numbers of people while the numbers of providers remain the same or shrink as budgets are reduced. Those services are provided in an atmosphere of perennial overwork on the part of the staff and frustration on the part of patients, who view the treatment they receive as an assault on their dignity, and experience discrimination, depersonalization, and disenfranchisement.

An additional effect of government efforts to maintain the status of the uninsured as marginal to the health care system is to reinforce negative attitudes about lack of health insurance among health care workers who deliver the message of being unwanted in the health care system in myriad ways to potential recipients of services—through specific policies such as querying each person about their health insurance status as well as more general aspects of the system, such as long waits. People in this research saw themselves as unwelcome in a system that prioritizes health care for people who have some sort of health insurance. Even if providers are unaware of a person’s precise health insurance status and are dealing with their own issues of being overworked and understaffed, uninsured people attribute their reception by health care workers to their health insurance status.

It should be noted, however, that the uninsured were not simply passive in the treatment they experienced. They actively worked the system, attempting to make it work to their benefit. Norwood (2006) observes that the margins are active, dynamic, and contested ground where agents negotiate for power and for place. This research has demonstrated how those who are uninsured persist in trying to get their health care needs met, using interpersonal skills and creative problem-solving, despite the system’s efforts to contain them.

The rationing of health care pervades this system, both directly and indirectly. Indeed, a willingness on the part of government to
allow one-sixth of the U.S. population to be uninsured is the most
dramatic form of rationing (Friedenberg 2003), but within public-
sector health care smaller-scale rationing is continuously taking
place as well. The basis of that rationing is economic rather than
clinical need. People are turned away from private care because
of lack of health insurance. When they are subsequently seen in
the public sector, they are often not given medications because it
is ascertained or inferred that they cannot pay for them.

Rationing also occurs indirectly, as people become weary of long
waits, impersonal treatment, and being shuttled around, and avoid
seeking health care as much as possible. Everywhere they turn, the
uninsured find negative attitudes because of their uninsured status,
and this unrelenting negativity is a further deterrent to use of the
health care system. Ultimately, they become discouraged from
using the health care system and try to use it as little as possible.
Although exclusion may be an unintended consequence of these
policies, it nevertheless works to give the appearance of keeping
the problem under control: if fewer people seek health care, the
problem appears more manageable.

The failure of health care reform in the United States in the early
1990s was the last serious attempt to include the uninsured in a
comprehensive health care system. But the public-sector system
was in place long before that. In the intervening years, policies of
containment have hardened as neoliberal ideology has overtaken
previous ideals about the role of the welfare state. Consequently,
these systems have become increasingly rigid. At the same time,
the public-sector health system has been in decline. Money is con-
tinuously siphoned away by the government while the numbers of
uninsured continue to rise dramatically. In practical terms that
means much greater difficulty in accessing health care and more
demeaning experiences for those who attempt to do so, leading
many people to avoid the health care system rather than suffer
recurring blows to their dignity. Such experiences are the antithesis
of the UN’s precepts of the right to health (UN 2000).

The limitations on health insurance availability do more than call
attention to disparities within a given society. They illustrate how
containment, as a strategy of governance, works imperfectly to
control the problem. Although the U.S. system may be seen as
functional in that most people do eventually receive care, it is
dysfunctional in the sense that the antipathy people experience
towards the system leads them to avoid it and, in the process, to
miss out on much needed health care. Systems that are unable to carry out their ostensible goals may be seen as dysfunctional, and public-sector health care in the United States is one such system. As a long-term strategy, the politics of containment may create increasing unrest and dissatisfaction among the populace, especially as the numbers of people affected by such policies grow and the problem becomes a symbol of other ills in society.

There are indications that public opinion is becoming less favorable to current neoliberal policies in the United States. Cris Shore and Susan Wright (1997) have observed that when people fail to identify with the policies of those who govern, the normative power of modern government has lost its ideological grip. Current U.S. polls increasingly report people’s views that the government is out of touch with respect to domestic policies such as health insurance. It appears that people in the United States have been under the sway of an ideology that may be losing its hold. As the number of uninsured grows and as most people have friends and relatives who are uninsured, even if they themselves are not, the rising groundswell of indignation may eventually be a catalyst for change in the U.S. health insurance system. Until that time, any gains to be made in providing health insurance to the uninsured are likely to be small.

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