

Who's Playing God?

—Analysis of the Grady Dialysis Crisis—

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The God Committee

Imagine the following conversation in a committee of seven people:

The housewife starts, “If we are still looking for the men with the highest potential of service to society, then I think we must consider that the chemist and the accountant have the finest educational backgrounds of all five candidates....”

“Both these men have made provisions so that their deaths will not force their families to become a burden to society,” the lawyer cuts in.

The state official hastily responds, “But that would seem to be placing a penalty on the very people who have perhaps been most provident....”

The surgeon, changing cases, speaks up: “How do the rest of you feel about Number Three—the small businessman with three children? I am impressed that his doctor took special pains to mention that this man is active in church work. This is an indication to me of character and moral strength....”

“It would also help him endure a lingering death....” the lawyer comments in a matter-of-fact manner.

This is not a scene from some fiction novel; the conversation actually took place in one of the meetings held by “the God Committee,” a seven-member panel formed in 1961 at Swedish Hospital in Seattle.¹ They were in charge of determining which patients should benefit from the then-very few hemodialysis machines.

¹ Levine 2009.

History of Modern Dialysis

To many, it was a moment of scientific victory over disease when Dr. Belding Scribner and his team at University of Washington had developed the first dialyzer and started treating patients on March 9th, 1960.² However, soon these pioneering health professionals faced a dilemma of triage because they had to choose a limited number of candidates for the expensive and scarce technology. In response to this ethical dilemma, the Admissions and Policies Committee of the Seattle Artificial Kidney Center at Swedish Hospital, or “God Committee” as it came to be called later, was established in 1961. It was a committee of seven unpaid citizens chosen by the King County Medical Society—a lawyer, minister, banker, housewife, state government official, labor leader, and surgeon. At their first meeting, the committee accepted kidney doctors’ recommendations to reject anyone over 45 because older patients were likely to develop medical complications. Children were also excluded because, it was felt, they might be traumatized by the procedure. At the second meeting, the members decided that they wanted to be anonymous and did not want to know the candidates’ names. The third meeting was crucial. The members came up a list of all the factors they would weigh in making their decision, including age, sex, marital status and number of dependents, income, net worth, emotional stability, educational background, occupation, past performance and future potential, and references. Without any prior guidelines, these decisions heavily depended upon the subjective criteria of social worth among the members.³

Today, most of us find the kind of discussion held by the God Committee to be deeply troubling; even the mere thought of certain individuals possessing the power to determine the life and death of others feels fundamentally wrong. We may want to think that such coarse selection over human life and its worth is long gone in the past—but is it?

² Rodriguez 2010.

³ Levine 2009.

Crisis of Ethical Care

“When I received that letter, I was like, ‘Oh No! What can I do now?’ I was really, really upset,” said Baani, a 27-year old woman originally from India who has been living in the US for 10 years now. She is petite, gentle, and lively; and she is undocumented. She had been receiving regular dialysis care for just a few months when she was notified that Grady was closing down its outpatient dialysis clinic. She told me:

One day, I was driving to my friend’s house and just fainted. When I came back to consciousness, I found out that my car had hit a pole. (...) They⁴ asked me, “What happened?” And I was like, “I don’t know.” So they took me to the doctor. (...) They [the doctors] asked my history and I told them that I had kidney failure six years back⁵. That’s when they told me I had to start dialysis and when I started dialysis, I felt, like, a hundred times better. My life literally came back. Before that I wouldn’t see my friends for months. I didn’t like go to anywhere. I wasn’t like dressing up or anything. Because it was new for me! Cuz before I used to wear high heels and everything. And with all those pains, it doesn’t matter whichever shoes I bought, doesn’t matter how expensive they are. I couldn’t walk. My feet started hurting from, like my sole, my legs used to hurt. Everything used to hurt. I couldn’t even walk. But when I started dialysis, gradually, everything came back on track. And I started going to church⁶, going out with friends, you know.

“So you felt much better,” I said. “Oh yeah,” Baani replied, “That’s why I was so upset when I got the letter [from Grady about the closure of the outpatient dialysis clinic]. I just didn’t wanna go back to *that*.”

In August 2009, the Grady Memorial Hospital announced it was going to close its outpatient dialysis clinic, which affected, among others, about 50 uninsured or underinsured patients

⁴ It was not clear from the interview who “they” are. It could be police officers who took care of the site of accident or her family members.

⁵ In theory, it is very rare, almost impossible, that an End-Stage-Renal-Disease patient survives for 6 years without dialysis or any kind of renal replacement therapy. Although I know that Baani is telling the truth, it may nonetheless be reasonable to assume that her kidney still maintained some degree of function when she was initially diagnosed as ESRD.

⁶ She is a devout Sikh.

with ESRD, most of them undocumented immigrants.⁷ Considering the fact that ESRD patients need dialysis usually three times a week to live, this sounded like a virtual death sentence to the patients as well as those who cared for them. Although some could find alternative care providers, the majority faced three options: to go to the emergency room whenever they felt critically ill; to move to a state where, unlike Georgia, undocumented immigrants can receive dialysis covered by Medicaid; or to go back to one's country to origin. A few activist groups, including Advocate for Responsible Care (ARxC), were formed following Grady's announcement. While Grady did close its outpatient dialysis clinic in October, they successfully negotiated with the hospital to continue the patients' dialysis treatment by contracting with a private company, Fresenius. The initial three-month long contract was then extended to one year through successful advocacy.

Eventually, on August 31st, 2010, the Fresenius contract ended. With a considerable amount of activism, media coverage and negotiation, however, a new settlement was reached on September 10th that enabled the continuation of dialysis treatment for all 38 patients—all uninsured and predominantly undocumented immigrants. According to the deal, three private dialysis providers—Fresenius, DaVita and Emory Healthcare—would take 13 patients as charity cases while Grady agreed to pay Fresenius \$750,000 to help continue the dialysis treatment for the remaining 25. This agreement, however, will be in effect only until September 1st, 2011, after which the patients will face another uncertainty.⁸

How Can This Happen?

The question is: HOW CAN THIS HAPPEN? Here, I will ask two further questions to answer this. First, why did the patients develop End-Stage Renal Disease (ESRD) in the first place? Second, why can't they have the dialysis treatment that they desperately need? Since the dialysis problem is roughly comprised of (1) the development of disease and (2) obstacles

⁷ Poole 2009.

⁸ Teegardin 2010.

for securing access to adequate care, I believe these two broad questions can serve as the gateway into our inquiry of this very complex phenomenon.

Question One: Why did the patients develop ESRD in the first place?

What Is ESRD?

ESRD, or End-Stage Renal Disease (also called End-Stage Kidney Disease or Kidney Failure), is the complete, or almost complete failure of kidney function. It occurs when the kidney is no longer able to function at a level needed for day-to-day life. It is almost always the case that Chronic Kidney Disease (CKD) has worsened to the point at which kidney function is less than 10% of normal, which is then considered ESRD. With the kidney's function to remove wastes from blood severely and irreversibly damaged, people with ESRD have only two options for treatment: kidney transplant or regular dialysis, usually no less than three times a week. Without dialysis, 2-3 weeks' worth of toxin accumulation in the bloodstream would be life-threatening.

The Case of ESRD among the 38 Ex-Grady Dialysis Patients

Importantly, all the 38 patients realized their symptoms of ESRD only *after* they came to the US, sometimes after years of living here.⁹ What could have, at least partially, contributed to the development of ESRD? Although the etiology of disease is complex, here I will examine two factors that could account for their negative health or, more generally, unequal health outcomes in contemporary US. The 38 patients all share two things in common: uninsured and undocumented.

Being Uninsured and ESRD

Some studies show that foreign-born residents of the United States are 3 times more likely to be uninsured than native-born residents. Among US foreign-born residents, noncitizens

⁹ Personal communication, ArxC 2010.

are twice as likely to lack insurance as citizens¹⁰. Therefore, it is reasonable to think that undocumented immigrants in the US are most likely to lack any kind of health insurance. Not surprisingly, lack of insurance is a serious obstacle to access to care. This difficulty in securing access to care at least partially contributes to the development of ESRD because uninsured patients with Chronic Kidney Disease (CKD) are more likely to miss timely care, progress from CKD to ESRD more quickly, and hence are more severely ill and in urgent need of ESRD treatment when they finally see a doctor ¹¹. Furthermore, being uninsured generally implies low socioeconomic status. Along this line, a number of researches have also demonstrated the causality between low SES and increased susceptibility to ESRD, especially when the leading cause is diabetes mellitus. Accessibility to treatment is an important factor by which SES leads to the progression of CKD and ESRD¹².

Being Undocumented and ESRD

As of March 2004, roughly one half of Mexicans living in the US were undocumented, accounting for 5.9 million (57%) of the 10.3 million undocumented immigrants estimated to be living in the country that year¹³. A number of studies have been carried out on health care utilization by undocumented Hispanic/Mexican immigrants, many of which have found out that they are no more, if not less, likely to utilize health care services than insured citizens¹⁴. In their study on the undocumented Mexican Immigrants in New York City, for instance, Nandi et al. conclude that the use of health services by undocumented immigrants was limited, and the relative lack of (1) ability to navigate the US health care system, (2) access to social resources, and (3) engagement with the formal economy was associated with limited use of health care services¹⁵. Some studies also show that the fear

¹⁰ Barry 2009:921.

¹¹ William 2007:68.

¹² Ward 2008:569.

¹³ Nandi, et al. 2008:2011.

¹⁴ Chavez, et al. 1992; Leclere, et al. 1994; Marcelli and Heer 1998; Nandi, et al. 2008.

¹⁵ Nandi, et al. 2008:2019.

and anxiety to be discovered by government officials also contribute to the delays in seeking care¹⁶. These findings resonate with what Baani, one of the 38 ex-Grady dialysis patients, told me: “I was told that I had kidney failure in 2003. They gave me prednisone, which I just stopped taking soon because it made my body swell so much. Everybody was telling me I was gaining weight because they didn’t know what was going on. Then I didn’t do anything. I was so scared. No, I didn’t even know I could go to the ER. I went into ER for the first time in 2009.”

Question Two: Why Can’t They Have the Access to Dialysis Treatment They Need?

The Difficulty in Receiving the Kidney Transplant

The dialysis treatment is of absolute importance for the undocumented immigrants with ESRD because the other option, the kidney transplant, is not feasible. The barrier is mostly economic. Public Law 92-603 passed in 1972, which granted every US citizen with ESRD the right to have dialysis treatment covered by Medicare, specifically bars federal reimbursement for “care and services related to a transplant procedure” for any “alien who is not lawfully admitted for permanent residence or otherwise permanently residing in the United States”¹⁷. The ineligibility to receive public funds means they have two options left: to buy private insurance or to individually raise the money to receive a kidney transplant. Considering the financial insecurity experienced by many undocumented immigrants and the fact that the total bill for the first posttransplant year can amount to \$200,000¹⁸, these options are simply unrealistic.

Contrary to the common misperception in the public, United Network for Organ Sharing (UNOS) does not bar undocumented immigrants from putting their names on the waiting list; its policy states that “no consideration in [organ] allocation is given to gender, race,

¹⁶ Ibid. 2017.

¹⁷ Goldberg, et al. 2007:17

¹⁸ Ibid.

citizenship or social factors such as wealth or celebrity status”¹⁹. Therefore, the obstacles for undocumented immigrants to receive kidney transplantation are largely economic, rather than legal.

Some argue that the federal bar against non-citizens is unfair on the basis that the undocumented contribute more organs to UNOS organ bank than they take from it (in 2005, the citizens received 96.2% of the transplants in the US whereas they donated only 94.8% of organs) or irrational on the basis that the point at which the costs of transplantation are less than those of continued dialysis can be as little as 2.7 years²⁰.

Moreover, even if undocumented immigrants find a way to overcome the economic obstacle, other kinds of barriers may still remain. In their study on kidney transplant waiting list, for instance, Kasiske et al. found out that patients who were younger, better educated, white, working full time, and had better health insurance coverage were more often listed before the first dialysis than those who were older, less educated, of a racial or ethnic minority, working less than full time, and had less insurance coverage²¹. Although this phenomenon could be explained by the different degree of access to health care in general, the authors nonetheless note the possibility of conscious or unconscious discriminatory practice in the current allocation system.

Neoliberal Policies in Health Care: The Politics of Inclusion and Exclusion

To date, ESRD is unique in that it is the only clinical diagnosis that automatically grants the patient the coverage by Medicare to receive continued treatment. This “universal coverage,” however, does not apply to undocumented immigrants; the US taxpayer money pays only for the emergency care of undocumented immigrants, which means those without insurance have to run into the emergency room every time they are fatally ill.

¹⁹ Ibid.

²⁰ Goldberg, et al. 2007:17

²¹ Kasiske, et al. 1998.

Things have not always been like the way it is now. When Public Law 92-603 that guarantees access to dialysis for those with ESRD was passed in October 1972, it did not mention citizenship as an eligibility requirement for funding. However, in 1986, the Omnibus Reconciliation Act was passed, making two significant changes that affected undocumented immigrants' access to care. First, it prohibited federal Medicaid payment for care of undocumented immigrants, except for emergency medical care provided to those who would otherwise be eligible for Medicaid. Second, it mandated that all hospitals receiving Medicare funds to evaluate and stabilize all patients coming into the emergency department regardless of their immigration status. Under the 1986 legislation, emergent dialysis must be provided to undocumented immigrants with renal failure, but federal Medicaid payments are not provided for maintenance dialysis therapy. The 1996 Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) was also an important legislation that affected all immigrants because it extended the prohibition on full-scope Medicaid benefits to many residing in the US legally (e.g. those who haven't been US citizens for more than 5 years). In addition, it explicitly denied all state and local public benefits to undocumented immigrants, forcing states wishing to extend public benefits to undocumented immigrants to pass new laws specific to their own state²².

The series of federal legislations and state-level policies have resulted in the absence of a national standard for the care of undocumented immigrants with ESRD²³. Today, if an undocumented immigrant lives in California, New York, North Carolina or Arizona, he or she is better-off than in the other states (such as Florida, Alabama or Georgia) because these are the minority of states that have decided to provide maintenance hemodialysis support for undocumented immigrants. They do so by broadly interpreting the scope of "emergency medical conditions" that makes care of undocumented immigrants eligible for Medicaid reimbursement. Emergency medical condition is defined broadly by federal legislation as:

²² Campbell, et al. 2010:183-5.

²³ Hurley, et al. 2009.

A medical condition (including emergency labor and delivery) manifesting itself by acute symptoms of sufficient severity (including severe pain) such that the absence of immediate medical attention could reasonably be expected to result in—(a) placing the patient’s health in serious jeopardy, (b) serious impairment to bodily functions, or (c) serious dysfunction of any bodily organ or part.²⁴

This broad definition allows each state certain flexibility to determine which care is “emergent” and therefore can be covered by Medicaid funds. For instance, in California, the state of the greatest estimated number of undocumented immigrants, approximately 1,350 of the more than 61,000 patients who are receiving dialysis support are undocumented. The cost of such care can amount to \$51 million a year²⁵. Like California, Georgia, the home state of Grady Memorial Hospital, had covered the dialysis therapy of undocumented immigrants—until 2006²⁶. The 2006 legislative modification reflected the concern about the long-term economic effects of maintenance dialysis care for undocumented immigrants.

The stream of legislation that has gradually and steadily restricted access to care for undocumented immigrants may reflect the overall neoliberal current that has come to permeate US health care policies. The 1996 PRWORA Medicaid amendments, for instance, had reduced enrollment levels among noncitizen children by 12 % from 1995 to 2001²⁷. The negative impacts are also visible among the children of low-income US citizens, who are more likely to face difficulty in providing necessary documentation for restricted enrollment²⁸.

Another example would be *Salud!*, a new Medicaid managed care implemented by the state of New Mexico in 1997. This “neoliberal, privatized model of health care delivery for a low-income, predominantly minority population”²⁹ generated a handful of unintended negative

²⁴ Hurley, et al. 2009:185

²⁵ Ibid.

²⁶ Campbell, et al. 2010:183-5.

²⁷ Rosenbaum 2007:264

²⁸ Ibid. 265

²⁹ Lamphere 2005:4

consequences, including (1) the increased difficulty and complexity in accessing care, especially for the poor and other marginalized groups residing in the rural areas, and (2) the increased bureaucracy and workload to secure reimbursement and help buffer their clients from new complexities, a task that fell particularly heavily on safety-net clinic administrations. Considering these effects, Lamphere explicitly critiques “an implementation of neoliberal policies that have created a bureaucratically complex system buttressed by discourses that emphasize competition, efficiency and individual choice³⁰.” What such a discourse overlooks, of course, is that there are certain vulnerable populations who are structurally barred from the resources necessary to fully realize their “individual” choice. Despite Lamphere’s critique, the privatization of health care and the slash in public funds for the underserved have been the salient characteristics of health care-related policies in the past few decades.

(3) The US Health Care System and the Financial Crisis of Safety-Net Hospitals

While a series of legislation that has gradually restricted undocumented immigrants’ access to health care over the last few decades directly accounts for the inability of ex-Grady patients to receive public dialysis support, it is the critical financial crisis experienced by providers—especially safety-net hospitals—that is largely responsible for Grady’s decision to close its outpatient dialysis clinic. The closure cannot be understood by simply condemning Grady as the “bad guy” who decided to cut patients’ lives to save money, although this view holds partial truth. The problem, however, is much larger.

Since it opened in 1892, treating underserved low-income families has been a major mission for Grady. For instance, Grady has long been seen as a hospital that primarily serves minorities—particularly blacks, who comprise 48 % of Fulton and Dekalb counties³¹ (see figure 1). Ever since the Fulton-Dekalb Hospital Authority took over the hospital’s operation from the city of Atlanta in 1941, it has been these two counties that make annual payments to Grady for the care of their indigent residents. This means that no other county

³⁰ Lamphere 2005:19. See also Boehm 2005; Willging 2005.

³¹ Dewan 2008.

makes annual appropriations to Grady's annual budget, despite the fact that one in ten patients Grady serves is from another county, often arriving in ambulance. For long, Grady has been the only safety-net hospital in the metropolitan Atlanta, attracting more and more uninsured and underinsured patients. In 2008, when the hospital's financial crisis shape was so grim that it threatened its continued operation, a third of Grady's patients were uninsured and only 8 % of inpatients fit the privately insured category³².

For the struggling hospital's management, the undocumented immigrants with ESRD who used to receive care at Grady's outpatient dialysis clinic unfortunately meant a growing number of uninsured for whom Grady could expect little reimbursement. Dialysis is not a cheap treatment. For example, Medicare spending for ESRD in 2003 totaled more than \$18 billion, a 7% increase from the previous year. The ESRD program now accounts for 6.7% of the entire Medicare budget, and ESRD costs per patient average \$55,000 or more annually³³. These costs usually fall heavily on the shoulders of safety-net hospitals such as Grady that provide disproportionate amounts of care to low-income and uninsured patients, whose numbers have been increasing nationwide in light of the recent economic downturn. Today, there are an estimated 46 million people in the US who are without health insurance, and many more are underinsured³⁴. The increase can be explained by three contributing factors. First, fewer working persons have employer-sponsored insurance. Second, public coverage in many areas has been restricted. Lastly, although the increase has been predominantly among young native-born US citizens, the influx of undocumented immigrants has also contributed to the rise in the number of the uninsured³⁵.

³² Dewan 2008.

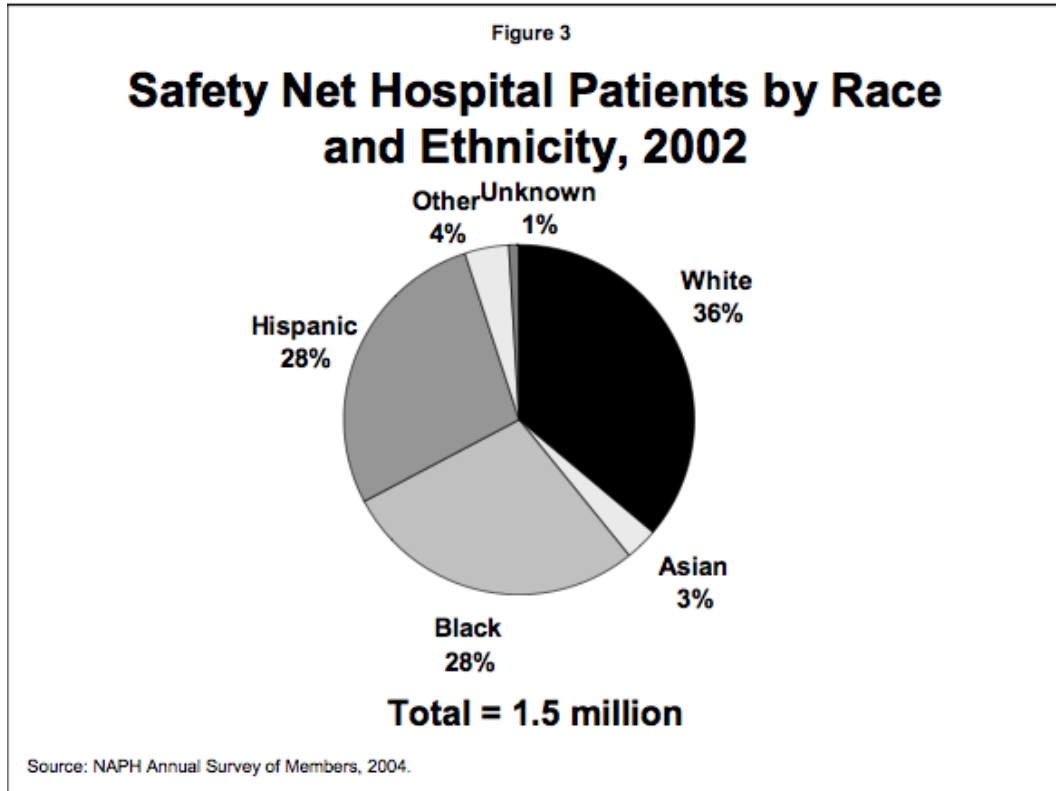
³³ Williams 2007:69

³⁴ Barry 2009:921

³⁵ Williams 2007:67

Not surprisingly, there are fewer and fewer public hospitals in the country. In 2008, for instance, there were roughly 300 fewer public hospitals than 15 years before³⁶. Many of the approximately 1,100 public, non-federal acute care hospitals that remain are also in dire

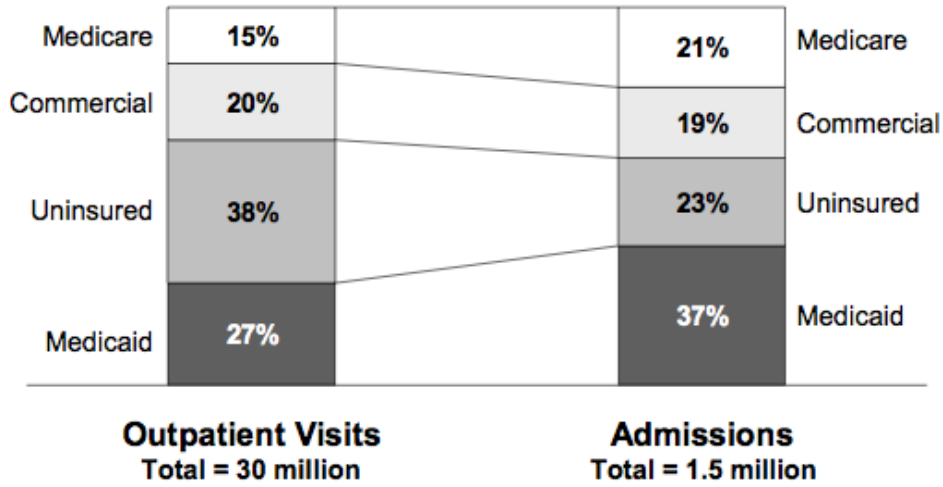
Top: Figure 1 (Regenstein and Huang 2005:6) Bottom: Figure 2 (Ibid. 5)



³⁶ Dewan 2008

Figure 2

Payer Mix, as Percent of Inpatient Admissions and Outpatient Visits, 2002

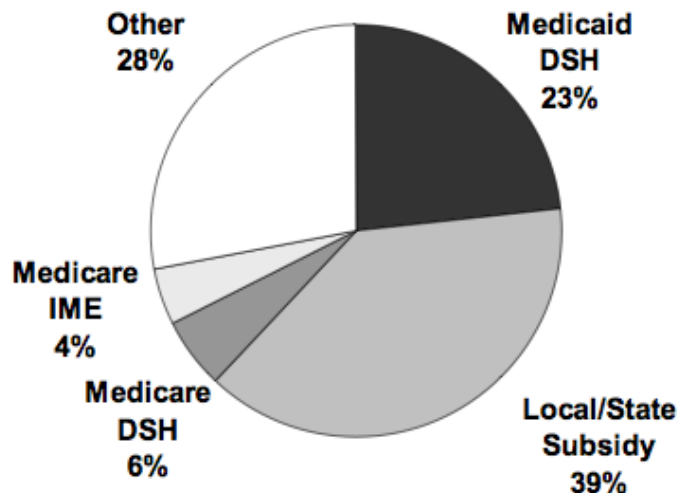


Source: NAPH Annual Survey of Members, 2004.

Top: Figure 3 (Regenstein and Huang 2005:8) Bottom: Figure 4 (Ibid. 9)

Figure 5

Sources of Financing for Unreimbursed Care at NAPH Hospitals and Health Systems, 2002

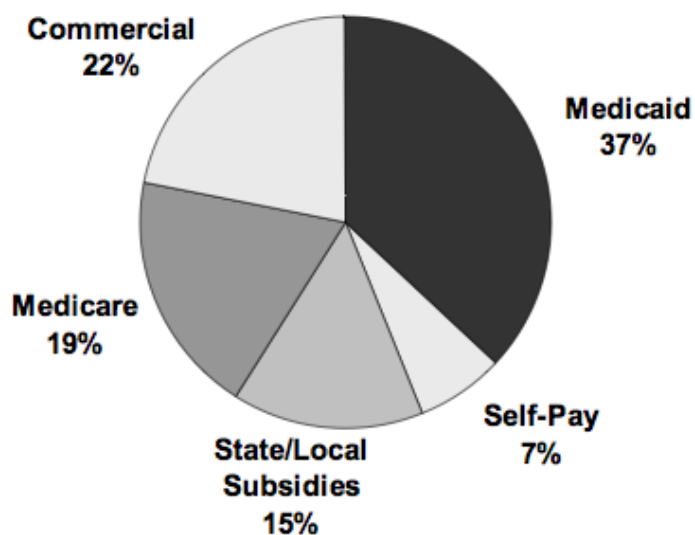


Total = \$8.9 billion

Source: NAPH Annual Survey of Members, 2004.

Figure 4

NAPH Hospital Net Revenues by Payer Source, 2002



Total = \$23 billion

Source: NAPH Annual Survey of Members, 2004.

financial shape. According to Regenstein and Huang's study on the public hospitals that are members of the National Association of Public Hospitals and Health Systems (NAPH)³⁷, nearly two-thirds of outpatients who receive care from safety-net hospitals are either uninsured or covered by Medicaid³⁸ (see Figure 2). When revenue from privately insured patients cannot be expected, the federal and local governments' funds are of increasing importance for safety-net hospitals. In fact, nearly 40% of all safety net revenues are from Medicaid³⁹ (see Figure 3 and 4). Medicaid is virtually "the workhorse of the U.S. healthcare system" and "the engine that fuels access to health services for individuals who rely on the safety net for their care"⁴⁰.

Yet, these financial supports have been decreasing; the authors' survey on key changes to the Medicaid program in 2004 and 2005 shows that there had been cuts in provider payments, benefit reductions, and eligibility restrictions put in effect by the state of Georgia⁴¹. The cuts in public support for safety-net hospitals seem to be increasing as governments, federal or local, are trying to reduce spending on public investments in response to financial crisis. For many safety-net hospitals that continue to face problems such as the increased demand for interpreter services, overworked employees and aging out-of-date equipments, the situation is and will be tough.

It is against the backdrop of an increasingly neoliberal health care system that Grady decided to install a private, not-for-private management board in 2007, which in turn voted for the hiring of new CEO Michael A. Young in June 2008. Surprisingly, Young transformed Grady into a profit-making hospital; in 2009, the hospital had about \$34 million in the black, which is quite impressive considering the fact that the hospital had a \$50 million

³⁷ The Grady Health System, which includes the Grady Memorial Hospital, is a member, too.

³⁸ Regenstein and Huang 2005:4-5

³⁹ Ibid. 1

⁴⁰ Ibid. 7

⁴¹ Ibid. 12-3

operating deficit two years before⁴². Among a number of drastic cost-effective measures Young has taken, of course, are the closure of Grady's outpatient dialysis clinic and the subsequent discontinuation of dialysis treatment for the uninsured, underinsured and undocumented.

Conclusion: Who Is Playing God?

In the age of biomedicine, disease is often seen as a discreet biophysiological entity. In this view, ESRD is nothing but a failed kidney within an individual organism. Our exploration of larger factors that influence the ongoing Grady Dialysis Crisis, however, has demonstrated that the problem is by no means contained in the bodies of 38 patients themselves, nor within the management of the Grady Memorial Hospital.

For one, the dialysis problem is a very real consequence of various social forces. The development of CKD, its progression to ESRD, the inability to receive kidney transplants and the difficulty in getting access to dialysis treatment among undocumented immigrants are all influenced by various forces, whether they may be psychological (discrimination in delivery of care, fear and stress that delays care seeking), cultural (language barrier), economic (income), structural (inequality in health care access), administrative or political (bureaucracy, legal status, and legislation).

Furthermore, the Grady Dialysis Crisis cannot be aptly understood without placing it in the context of political economy of health. The privatization of health care has been intensifying in the recent climate of neoliberal policies. The decreasing public financial support for undocumented immigrants with ESRD *as well as* for safety-net hospitals like Grady are, directly or indirectly, contributing to the Grady Dialysis Crisis. While the ethical discussion about what providers should do and what patients deserve remains critically important, the political-economic discussion about what doctors can afford to do and how patients are economically and politically excluded from certain options is of equal

⁴² Schneider 2010

significance. In any case, the facile discourse of cost-efficiency and individual choice should be met with caution.

Yet, the prospect is grim for these undocumented patients. The current contract between Grady and private dialysis providers under which they receive dialysis will end in August 2011. Although Baani firmly told me she had never lost hope, it will be another life-or-death uncertainty for her as well as for others.

When a 1962 *Life* magazine exposé revealed that the Seattle God Committee disproportionately allocated dialysis to white, employed men, public outcry was sharply directed at the Committee⁴³; although the members were anonymous, people knew there were seven people “playing God.” Today, although anxieties about unequal health care access continue, there are no mysterious seven figures to direct our anger to. In their ongoing struggle for their lives, the 38 patients and those who care for them will see if they can be heard by God, instead of being “played.”

⁴³ Goldberg, et al. 2007

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