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**From Co-payments to Rent Payments: Value and Vulnerability in the Grey Economy of
U.S. Healthcare¹**

There may be some people that just feel like, okay, even though I am a mother, I am still going to do all of these things and in today's economy, you can't.

-- "Evelyn," Medical Center patient²

[W]e are moving forward and sometimes it is very difficult because...you don't have things, you don't have enough resources...But thanks to God...things are moving along well...

-- "Honoria," La Clínica patient

As you walk through the waiting areas at Medical Center or La Clínica, you are met with the sounds of ringing phones, buzzing fluorescent lights, babies crying, receptionists checking patients in, and medical assistants calling patients' names. Pregnant women sit in padded chairs, waiting for their prenatal care appointments, scrolling on their phones or chasing after small children, sometimes accompanied by a bored-looking dad. At Medical Center, there are TVs on low volume in the background. At La Clínica, kids play in the nursery area. On any given day,

¹ This paper is an abridged draft of Chapter 2 of my dissertation, "Emergencies that Count: Pregnancy and the Politics of Care in the U.S." This dissertation is based on 15 months of ethnographic and historical research on differing conceptions of pregnancy-related emergencies in southeastern Pennsylvania. The National Science Foundation (Doctoral Dissertation Improvement Grant #1226738), the Wenner-Gren Foundation (Dissertation Fieldwork Grant #8616), and the University of Pennsylvania funded the data collection phase of this study. This abridged draft is for the review of the April 2014 Penn DCC Graduate Workshop participants. Please do not cite or circulate. This research would not have been possible without the time, insights, and assistance of the staff and patients at Medical Center and La Clínica, as well as from health experts and advocates.

² This and all other personal and institutional names are pseudonyms. All identifying details have been altered or omitted.

these clinics are packed. I met the women quoted above during fieldwork at these clinics, two of the remaining sites for prenatal care in southeastern Pennsylvania.

The first quote comes from a woman that I interviewed at one of Medical Center's obstetrics clinics. Medical Center is a major academic health system, serving tens of thousands of patients every year. The Medical Center prenatal clinics where I conducted fieldwork³ are unique in the giant regional health system in that they are geared specifically towards Medicaid-insured pregnant women from the greater Philadelphia area. At these clinics, prenatal patients are seen by medical assistants, residents, nurse care coordinators, and sometimes attending physicians for routine prenatal care. The clinics operate Monday through Friday, with one day per week designated as a 'high risk clinic' day - that is, the day of the week set aside for high risk patients. During high-risk clinical days, specialized staff members are on hand to evaluate women like Evelyn, with medically complicated pregnancies.⁴ Importantly, all of these women were insured during their pregnancies. These Medical Center clinics, like many prenatal care sites in southeastern Pennsylvania, do not routinely take on uninsured patients.⁵ Typically, this third-party insurance coverage is through one of the region's Medicaid Managed Care plans. Such coverage and the care it enabled was interwoven in women's descriptions of their pregnancies with everyday concerns about money and support: how to make rent, pay for childcare, and plan for the future.

The second quote comes from a woman that I interviewed at La Clínica, a small, non-profit health center in rural southeastern Pennsylvania. This nurse-run primary care clinic serves

³ I conducted on-site interviews at one clinic and participant-observation with follow-up interviews at a separate clinic.

⁴ These patients' medical conditions ran the gamut from gestational diabetes through pre-eclampsia to rare fetal anomalies requiring complex surgeries.

⁵ One key exception to this generalization is a Spanish-language clinic at Medical Center. Open only 1.5 days per week and geared in particular toward undocumented immigrant women, it is one of the few sites within the Medical

primarily Spanish-speaking immigrants, many of who are undocumented. At La Clínica, medical assistants, midwives, and sometimes nurse practitioners see pregnant women. If a patient needs a higher level of care than can be provided on-site, the staff will refer women out to a specialist in the area, usually one with whom La Clínica has a collaborating agreement. Unlike the women at Medical Center, the women at La Clínica are typically uninsured. Usually, they are also ineligible for Medicaid because of immigration status. These women pay out of pocket for the heavily discounted prenatal care that La Clínica offers. If a woman, like Honoria, needs a higher level of care, her options for insurance coverage are limited. Typically, she must enroll in Emergency Medical Assistance, an obscure part of the Pennsylvania state Medicaid program that provides temporary, third-party insurance coverage to people with emergencies - including, in some cases, medically complex pregnancies. Otherwise, she must seek out hospital-based charity programs, or pay the entire cost of her care. As at Medical Center, women's descriptions of their experiences during pregnancy intersected with economic concerns large and small: how to pay extraordinary hospital bills, the lack of affordable childcare, and losing a job.

Value and Vulnerability

Questions about value and human life loom large both in public debates about U.S. healthcare reform and in scholarly debates among medical anthropologists. While these scholarly questions typically emerge in relationship to the moral tensions raised by new biotechnologies, humanitarian interventions, and the unequal distribution of disease (*see esp.* Marsland and Prince 2012), I argue that the third-party payer system of health insurance in the contemporary United States provides a unique vantage point from which to consider questions about how the value of

Center health system that regularly takes on uninsured pregnant patients for routine prenatal care. Throughout the city, there are ## community health centers that will also accept uninsured patients for routine prenatal care.

life is negotiated. I build on recent ethnographies of U.S. prenatal care as a site of legal subject-making (e.g. Bridges 2011, Galvez 2011) to argue that pregnancy provides a specific point of entry into market subjectivity for women who may otherwise not be able to access healthcare. By market subjectivity, I mean the conditions of possibility for participation in U.S. healthcare markets. Because healthcare access is not guaranteed outside of an emergency room in the U.S. today⁶, pregnancy is one of a few moments in which women who are otherwise uninsured or uninsurable can gain entry to what I call the grey market of U.S. healthcare.

In this chapter, I make two related arguments about vulnerability and value. First, I show how women like Evelyn, Honoria, and many others like them become tethered - or untethered (Petryna 2002) - to the grey market of U.S. healthcare by making potential future forms of harm visible. Specifically, I show how pregnant women, their healthcare providers, and local advocates leverage particular forms of state-defined vulnerability to gain insurance coverage, one primary form of currency in the grey market of U.S. healthcare. I demonstrate that pregnancy combined with a lack of money and employer-based insurance - pregnancy plus poverty, to paraphrase a Philadelphia-based health advocate - becomes a formula for asserting vulnerability that is legible to the state. This legibility can then sometimes be transformed into currencies accepted in the grey market of U.S. healthcare, like Medicaid cards, at particular points of durability in the social safety net. Throughout, I show how selective forms of “emergency thinking” shape this process of tethering, wherein women’s lived experiences of precarity may come to the fore or become obscured (Scarry 2011). This mode of social inclusion differs from “biological citizenship” (Petryna 2002) in that individuals are not trading present proof of harm

⁶ I discuss the Emergency Medical Treatment and Active Labor Act - the law that prevents Medicare-participating hospitals with Emergency Departments from turning patients away - in Chapter 4.

for citizenship rights. Rather, they are attempting to transform potential future harms into currency accepted in the present-day grey market.

Second, I show how these bureaucratically legible forms of vulnerability are at odds with the forms of vulnerability and value that pregnant women themselves emphasize during pregnancy-related care. As women describe their experiences of pregnancy, the challenges that they face, and their hopes for the future, distinct discourses of vulnerability and value emerge. In these stories, looking for childcare, making rent, buying a house, getting - or more often losing - a job during pregnancy, and other concerns about *social* reproduction become salient. For pregnant women at Medical Center and La Clínica trying to gain a toehold in the grey market, what is valuable in and about life is decoupled from the vulnerabilities that are worth something in that market. Attention to such ordinary conceptions of value points to “endurance” (Povinelli 2011) as a useful rubric for understanding how women survive, live, and dream big in and beyond the grey market. Like “political acts of valuation,” these *personal* acts of valuation shed light on “the ways that people determine, enact, represent, and evaluate that which matters to them” as they pursue varied forms of social (and in this case, biological) reproduction (Cattelino 2008: 3). Thus, women’s own descriptions of carving out lives for themselves and their (future) children amid economic precarity illuminate alternative notions of value in and of life.

This analysis complicates anthropological understandings of the U.S. health system as a form of biopolitics or site of structural violence. Previous anthropological research has roundly critiqued the ill-effects of the public-private partnerships that have characterized U.S. healthcare since at least the advent of managed care. Scholarship in this domain has focused on the racial and class dynamics of exclusion (e.g. Rylko-Bauer and Farmer 2002), selective inclusion (e.g. Ong 1995), and forms of hyper-governance (e.g. Bridges 2011). Historical scholarship on U.S.

healthcare has meanwhile shown how popular concerns about social reproduction and social citizenship have been central to alternative healthcare economies at different points in recent U.S. history (e.g. Morgen 2002; Nelson 2011). As I show below, the United States' unique third party payer system and the grey market it has generated can be understood as a key site for asking questions about the valuation of life and diverse possibilities for social citizenship in the U.S. today.

The U.S. Health System as a Grey Economy

Marty Moss-Coane: And speaking of sticker-price, there is such variability as we know when it comes to pricing, it's very confusing... Why can't we just have a retail price and leave it at that? Why do we have seven prices for something?

Ezekiel Emanuel: Well so, this is one of the complexities of the healthcare system. First of all, it's exceedingly expensive.... Then there are, as you point out, six, seven different prices - actually there's more than six or seven, I just classified six or seven... There's the charge, that's the sort of sticker price that no one really pays unless you are paying out of pocket... then there is the Medicare price, then there is the commercial insurance, so if you have Independence Blue Cross or you have Aetna, that's- each of them will have a different price that they'll negotiate. There's a Medicaid rate, which tends to be low. There's the reasonable cost, which is what happens when an insurance company doesn't have a contract with a hospital, and they decide what they are going to pay. All of these prices are crazily different-

MMC: And then there is the actual cost...

EE: Right which no one knows, for most everything, which is, what does it cost to actually do this, because we haven't done the kinds of studies that'll define clearly the cost of the operation

or the procedure. And that is one of the insanities of the system. And the worst part of it is, if you have no health insurance, you get charged the highest price! You have no bargaining power. And that has to change.

--Marty Moss-Coane and Ezekiel Emanuel, on WHYY's *Radio Times*, March 11, 2014

In this chapter, I use the terms “grey market” and “grey economy” interchangeably to describe the third-party payer system of healthcare service delivery in the U.S. today. This usage departs from scholarly work on grey markets, which focuses on illegal or para-legal transactions (e.g. Roodhouse 2013). Here, I use these terms to refer to the ordinary market interactions in contemporary U.S. healthcare - obtaining an insurance policy, making a co-payment, billing for services, and especially getting information on the full cost of care - the terms of which are far from clear or highly variable in the experiences of the patients, providers, and advocates with whom I spoke.⁷ I develop this framework as a shorthand alternative to the common term ‘healthcare system,’ which implies a level of predictability and systematicity in healthcare-related interactions that only sometimes exists for patients and staff on the ground.⁸

As indicated in the block quote from *Radio Times* above, information about the prices of medical equipment and services is often unknown, unknowable, or so highly variable that it becomes difficult to track. Large group insurers have the ability to collectively bargain for lower prices for their customers - promising hospitals patient volume in exchange for better rates. By contrast, individuals do not. As well, hospitals, insurers, and other players in the healthcare

⁷ While I use these terms to highlight the ambiguities in these exchanges, I take seriously the racialized connotations of language and color, especially when describing exchanges that ultimately concern people’s bodies. As I offer these terms as a framework for thinking about healthcare markets in the U.S., I simultaneously ask: what does it mean to use the term “grey” to signify ambiguity?

⁸ As I describe further in Chapter 3, regional systems for delivering perinatal care have played an important role in historical imaginaries of reproductive healthcare. [Note about Parsons, etc on healthcare as a system?]

system are not routinely required to report on pricing data in any centralized or comprehensive way.⁹ News stories that try to track the cost of care across hospital systems, for example, highlight the highly variable cost of something as common as having a baby, even in cases of normal, healthy deliveries (e.g. Rosenthal 2013).

As I discuss in more detail in Part 1 of this chapter, federal regulation of this market has increased considerably as a result of the 2010 passage of the Affordable Care Act. Indeed, many of the most egregious practices of insurance companies - rescission, lifetime limits on payouts, and gender-rating, to name a few - are now illegal. There are important data collection provisions for Medicare-participating hospitals, aimed at improving knowledge about concerns like patient safety and the quality of care. Yet, insofar as it bolsters the third-party payer system of healthcare, the Affordable Care Act bolsters this grey market. As I will show, although the Affordable Care Act facilitates some individuals' participation in the health system, this participation is contingent upon individuals' ability to pay for care. And while that care has to some extent become more affordable, many people still struggle to gain entry into the grey market at all. I am not suggesting that a 'better market' - one with more price transparency, for example - would necessarily lead to better care or better health. Rather, as I argue below, individuals and the nurses and doctors who care for them must often leverage particular forms of biological and social debility to tie into and navigate through this grey market in order to get healthcare. In the case of pregnant patients, this often involves the language or claim of emergency. At the same time, women's experiences of pregnancy and motherhood point to alternative formulations of vulnerability and value in/of life beyond the grey economy.

⁹ [Check on new Medicare price reporting requirements] For example, there is no national databank on the prices of medical goods and services. Ironically, because Medicare is the largest insurance program in the U.S. today, there is (relatively) good information about the cost of procedures that Medicare is frequently called on to pay for, like hip

Part 1: Medical Center [cut for space]

Evelyn's story: high risk pregnancy and building the right kind of support network. Analysis of ACA and how the Healthy Pennsylvania Plan to expand Medicaid 'doubles down' on vulnerability requirement. Story about how if you lack support, you "fall off the edge."

Part 2: La Clínica

At [La Clínica], we walk this line. We know what good healthcare is, we know what good outcomes [are], we definitely bring people up to the highest level of functioning, but there are times when they need something and we can't get it. Unless we have a program, a grant, like [the breast cancer screening] project or family planning or something there that takes this on...there are some people that won't get simple things.

--La Clínica staff member

In this section, I describe how La Clínica itself is a point of entry for pregnant women into the grey market of U.S. healthcare. Its unique history in the landscape of maternity care and the commitment of its staff members to going above and beyond for the clinic's mostly-immigrant patients ensure that pregnant women who are otherwise cut out of the grey market can get some forms of pregnancy-related care. Specifically, they can get primary care from nurse practitioners on-site; referrals to specialists and social services as-needed; and help applying for Emergency Medical Assistance.¹⁰

replacements. Yet, price information remains scarce for services that Medicare patients do not require, like pregnancy-related services. By definition, Medicare patients are over 65 and thus no longer having babies.

¹⁰ Occasionally, a patient's status as a documented immigrant or U.S. citizen will make her eligible for Medicaid. In such cases, staff members work to enroll patients in 'regular' Medicaid rather than Emergency Medical Assistance.

The history of La Clínica demonstrates the financial and social balancing act that staff members must continually perform as they work to provide care to their patients. Throughout the clinic's history, staff members have worked grant by grant, cash payment by cash payment, to provide care to the mostly-immigrant communities in this rural corner of southeastern Pennsylvania. As indicated in the quote above, even "simple things" can be difficult to get. Although a recent influx of federal funding has helped ease some of these constraints, working in these conditions still requires, as one founding staff member put it, considerable creativity (Hallowell 2013).

Typically, maternity patients at La Clínica receive their prenatal care onsite from a medical assistant and a midwife. Labs are drawn on-site and sent out to one of the locally contracted labs that provide free or low-cost analysis services to La Clínica patients. When it is time to deliver, maternity patients typically deliver at nearby Hospital J. If they need specialized care, like an eye exam or an endocrinology appointment, they are referred to a specialist in the area, typically one with whom the clinic has a collaborating agreement. If the midwife's initial assessments show that a pregnant woman is too high risk for the nurse-run practice, then she refers that patient to a collaborating Ob/Gyn in the area. If a patient, for whatever reason, does not want to deliver at Hospital J, she can also choose to go elsewhere for her prenatal care or her delivery.

Cost and language, however, complicate this system of referrals and collaborating agreements. When a patient needs to see a specialist, the cost of the appointment and the language capabilities of the specialist's office come to the fore. Even though La Clínica has established relationships with area specialists who have some kind of Spanish language ability onsite and some flexibility with respect to payment, there is an incredible amount of work to be done for each appointment and each patient. For example, many La Clínica patients do not have

a bank account or access to credit, while many specialists do not accept cash payments.

As well, many specialists have some access to translation services, but this may be limited. When no translation services are offered at a given specialist's office, a medical assistant must work with one of the clinic's social workers to see if someone from the clinic can accompany the patient, or with the patient to find a bilingual family member who can accompany them. The medical assistant also works with the specialist to see what if any discounts are available to the patient. For example, sometimes if the patient is able to pay up front for the entire cost of her speciality care, the specialist's office will grant her a discount. In other cases, La Clínica has negotiated free care for its patients, as in the case of pregnant patients in need of dental care. To allow time for the patient to get the money together to pay for this specialty care, the medical assistant must also juggle the timing of the appointment, sometimes scheduling it a few days or weeks out. Occasionally, after putting in all this work, the patient will react negatively – trying to negotiate further with the medical assistant, for example, or balking at even the discounted cost of the appointment, which may still be hundreds of dollars. And, a lot of work can come to naught if the patient still cannot afford the discounted price of the appointment.

Thus, the lack of insurance coverage and the limited availability of Spanish-speaking healthcare services for pregnant women combine to turn 'just making an appointment' into a highly choreographed event. It requires a delicate back-and-forth between La Clínica, the specialist's office, and the patient. The amount of work that goes into this – the time it takes the medical assistant to negotiate a price, transportation, or translation services – can unravel when a patient cannot get the money together in time, or if her ride to the appointment does not show up. Adding to this precarious choreography is the ever-present reality that a specialist can simply refuse to take on a patient for any number of reasons, like the inability to pay. In such cases,

where a woman needs a higher level of care than the nurse practitioners and midwives at La Clínica can provide, the only recourse may be to send her to an emergency room. An emergency room, unlike a free-standing practice, cannot refuse to take on a patient because of her inability to pay.¹¹

As we saw at Medical Center with Medicaid, and as we will see in the next section with Emergency Medical Assistance, obtaining these insurance policies, however limited, is one of the few points of entry for women who are otherwise untethered to the grey market. Indeed, as we will see in the next section, Emergency Medical Assistance is one of the only forms of grey market currency available to uninsured and uninsurable women.

Emergency Medical Assistance

Beth: You were telling me a little bit about [your] resources and work – did you have to leave work or did somebody lose their job...

Honoraria: It's that...we used to work, my husband and I we worked, and I had to stop working because it was very dangerous work and...It has been very difficult because ...our expenses have been going up like with appointments and things like that, he's the only one, the costs fall to him and as well recently the amount of work has gone down....he has been very worried because he hasn't had a lot of work and the doctors appointments are very expensive....

Beth: I imagine so...

Honoraria: ...but...we are...we are very happy...It doesn't affect the basics....I think most of it has passed as well but...the two times that I went to the hospital, it's that...I still don't have insurance yet because...during [the] time that I [have been] pregnant, health insurance, I didn't get it through my job because I left my job, they were about to give it to me but now I don't have

¹¹ [Double check interview transcripts for accuracy]

insurance....but the bills from the hospital arrived already and we don't know what we are going to do...But they are saying it won't be long until it comes and covers the bills from the two hospital visits...But...It will be a good thing[motherhood], you have to stay positive, through all things, good or bad...

You are seven months pregnant with your first baby. All of a sudden you start having contractions. Your pregnancy has been complicated, your blood sugar is high, you have no insurance, you had to leave your job, the bills are mounting, and now you have to go to the emergency room. Twice. This was Honoria's situation, in the weeks leading up to our interview at La Clínica. This was her first pregnancy, and it was unplanned. She had been told for more than five years that she would not be able to have kids. She and her husband had considered fertility treatments, but could not afford them. When she began having symptoms of what she thought was a stomach infection the previous spring, she and her husband were distraught when the doctor suggested it could be a pregnancy. Not because they didn't want a baby - they did - but because they had been told for years that they would not be able to conceive without fertility assistance. So when her pregnancy test came back positive, Honoria was elated. She was also worried, she explained, because a baby "wasn't in our plans."

Honoria's complications began two months before I met her. She was first diagnosed with anemia, and then with high blood sugar. She also began having early contractions, for which she went to an emergency room twice. As we talked after one of her prenatal appointments, just a few weeks before her due date in the winter of 2012, she repeatedly thanked God that things were "moving along well." But, she explained, "sometimes it is very difficult because...you don't have things, you don't have enough resources." She had to leave her job

because of the danger it posed to her pregnancy. And since then, as she describes in the block quote above, the mounting costs of her prenatal care - and of daily living - have fallen to her husband. She and her husband are alone here in the U.S., save for a few friends that have helped them through this turbulent time. Meanwhile, she explained how she missed her own mother, who was back in El Salvador with the rest of her family. They talk on the phone, but it was not the same as being able to visit, or having her live nearby.

To help with these mounting costs, the staff at La Clínica had helped her apply for a temporary form of insurance called Emergency Medical Assistance, as Honoria describes in the quote above. Part of the Pennsylvania state Medicaid program, Emergency Medical Assistance is essentially temporary insurance coverage for people who would not otherwise qualify for Medicaid – in cases like the patients at La Clínica, usually because they are undocumented immigrants. Emergency Medical Assistance may last a few days or a few months. It is one of a very few points of durability in the safety net of pregnancy-related care for the uninsured and uninsurable.

In Pennsylvania, as in other states that offer the Emergency Medical Assistance program, the intent is to ensure that hospitals that take on uninsured patients too poor to pay for their healthcare are able to get reimbursed for the services they provide. Because active labor and delivery are legally defined as medical emergencies under the Emergency Medical Treatment and Active Labor Act, hospitals can typically apply for and receive reimbursement for the costs of providing labor and delivery services to uninsured pregnant women whose incomes fall below the program's cut-off line.¹² As well, healthcare providers who see patients prenatally can sometimes also apply for this coverage for their patients, provided that their patients meet

¹² I describe the history of this law and the inclusion of labor and delivery as emergency medical conditions in chapter 4. [Cites from interviews?]

income guidelines and are deemed sufficiently emergent or high risk by the medical review board at a local county assistance or district office. Applications can take up to 45 days to process, and letters of medical necessity must be included in the application.

In the best of cases, Emergency Medical Assistance will retroactively cover the medical expenses that a woman incurs and for six weeks following delivery.¹³ Yet, as providers and advocates alike explained to me, ‘the best of cases’ was increasingly hard to come by in the months following the 2013 federal budget cuts known as the Sequester. Fiscal austerity at the federal level manifested as funding cuts for programs like Emergency Medical Assistance at the state and local levels. For Honoria, this meant that two trips to the hospital Emergency Room – although likely to be covered by her pending Emergency Medical Assistance application – still generated huge bills in the increasingly long meantime while she waited to hear about her approval. And, even if she were to receive Emergency Medical Assistance, it would not cover bills unrelated to the “emergency” for which she was granted coverage. This is to say that the emergency care related to her contractions, for example, would be paid for; her routine prenatal care at La Clínica may or may not be. As well, this coverage may not cover treatments for other conditions deemed unrelated to the hospital visit or early contractions, like her high blood sugar.

Claiming Emergency

If possible and helpful, it may be useful to explain what might happen if the immigrant does not get the requested treatment. It is important to let the state know if the immigrant will suffer terrible health consequences (paralysis, death, etc) or need very expensive emergency treatment

¹³ [Check all numbers against interviews for accuracy.]

(ex. surgeries) if they are not given EMA [Emergency Medical Assistance]. This increases the chance of an approval.

-- Pennsylvania Health Law Project, 2011. Immigrant Health Care Manual for Advocates. P.18

Honoria is ‘lucky’ in the sense that the staff at La Clínica expected that she would be eligible for Emergency Medical Assistance. Not everyone is so lucky, as not all forms of distress during pregnancy can be made legible to the county and state officials who oversee the Emergency Medical Assistance program. Indeed, uninsured patients can be deemed ineligible for this program for any number of reasons: lost paperwork, having a form of distress that does not qualify as an Emergency Medical Condition under the Emergency Medical Treatment and Active Labor Act, or not being emergent or high risk ‘enough,’ per the review of a given county’s medical review board. Aside from this program, hospital-based charity care programs are typically the only other way that uninsured La Clínica patients receive financial assistance with the often-astronomical bills that even a brief emergency room visit can generate.¹⁴ Thus, as I describe below, a lot of work goes into making the case that a woman’s distress during pregnancy translates into an approved Emergency Medical Assistance application.

In all applications for Emergency Medical Assistance, medical and legal notions of what counts as an emergency must be made to overlap. As the advocacy handbook quoted above notes, an Emergency Medical Condition for the purposes of an Emergency Medical Assistance application may not require a physical trip to an emergency room; it may not be an emergency, by medical standards, at all (Pennsylvania Health Law Project 2011). Normal active labor and

¹⁴ After my clinic-based fieldwork ended, I sprained my ankle and was admitted to one of Medical Center’s emergency rooms. During a relatively short visit, I saw a triage nurse, a physician’s assistant, and an x-ray tech. I had one set of x-rays taken and was discharged with a pair of adjustable crutches, an Ace bandage, and 800mg of

delivery, for example, is a case in point. Active labor and delivery are considered Emergency Medical Conditions for the purposes of applying for Emergency Medical Assistance, even if the labor and delivery are uncomplicated, short, and both the mother and the baby are healthy. As such, hospitals can apply for reimbursement from the Emergency Medical Assistance program even if a healthy pregnant woman (without insurance) comes in to deliver. In other cases, like Honoria’s emergency room trips for contractions, someone – often the staff at La Clínica – must compile a detailed application. The clinician typically must write a letter with the required forms and the patient’s chart, so as to make the case that an Emergency Medical Condition is clearly present and will have potentially catastrophic consequences for the woman or her baby. Applications may include evidence that the condition for which the woman requires care may also incur enormous costs in the future, if not treated before it becomes more emergent. In this way, clinicians and advocates work to render a particular woman’s distress in written text legible to the bureaucratic processes of the state.

Once this work has been compiled, the application is then reviewed at the county or district level. Yet, the approval process is opaque and highly idiosyncratic: in the words of one health advocate, “if you have seen one County Assistance Office, you have seen one County Assistance Office.” These offices are under the leadership of regional directors, some of whom – according to one advocate – define “life-threatening” more narrowly than others. Some offices currently require proof that the patient is in “imminent danger of hospitalization.” Many send the decision up to a managerial level for further review and approval. Conditions like gestational diabetes, a common threat to the health of mothers and babies at both La Clínica and Medical Center, are the kinds of conditions that shed light on the tensions in the definition of ‘life-

ibuprofen (i.e., four Advil). This short, straightforward visit was billed, however, at XXXXXXXX. Because I have a robust employer-based insurance plan as part of my graduate school-funding package, I only paid about \$130.

threatening.’ Gestational diabetes is relatively straightforward to diagnose and treat. If diagnosed early, it costs a relatively small amount of money to manage and take care of throughout a pregnancy. It is also very likely to cause significant medical problems for both mother and baby if not caught in time or properly managed. Yet, gestational diabetes may be deemed not sufficiently “life-threatening” as to warrant Emergency Medical Assistance for a number of reasons, including that it is not an “immediate” threat to life. When applications are rejected, the process starts all over again. In the meantime, Honoria and women like her must wait.

“She helped me feel like it was worth it all”

Isabela: [My counselor] helped me a lot...she came once a week to my house to give me energy (darme ánimo) so I did not feel alone and I am very grateful to her because she helped a lot....she helps a lot of women and she helped me a lot. When she first came to my house I didn't want her to leave because she gave me a lot of energy and she helped me a lot. For my whole pregnancy.

Beth: [Was that] the Programa de las Promotoras?

Isabela: yes it was the Promotoras program....I was put in touch with her and she came and looked for me and came to my house and everything was good...

Beth: That's so great, that they have programs for moms like that...

Isabela: Yes because it supports us, we feel better, and my self-esteem I think was in the dirt and she reanimated me and I felt so much better and so for that reason I think my pregnancy was calmer...

Beth: how wonderful....did you have this during both of your pregnancies or just your first one...

Isabela: no just during my second pregnancy...

Beth: oh that's great...better than not at all...

Isabela: yes...Much better because she helped me so much, she treated me so well, she helped me feel like it was worth it all....like I had stopped working, I had stopped doing a lot of things because of the pregnancy, to care [for] the pregnancy, like when I left work I felt bad. I felt like what am I going to do, I can't work, or anything...But she made me feel like I could....

Beth: When you think about the future with your kids, of your family [or] yourself, what [do] you think about?

Isabela: Well I think that I want to learn a lot of things...For myself but also for my kids too because I want them to feel proud of me one day. Like for example my daughter keeps telling me to take English classes and so I am looking into English classes and my daughter said she would like to learn how to swim[,] so I went to the Y to get an application so they could help me get her what she needs so she can take her swimming classes....I want to bring myself up in this country and move forward without any fear of anything (Lo que quiero es superarme en este pais, salir adelante, sin miedo a nada) because sometimes things are difficult for me because I don't speak English[,] so I want do things that I can't because they are in English and so my goals are to learn English, and help my daughter with what she want to do, like her swimming classes....and well move forward (y pues salir adelante)...We are happy now, my husband is good now and we have a lot of future plans...

As we talked on a cold December afternoon, Isabela explained to me how her visiting health advocate supported her during her second pregnancy. This lay health educator visited her, encouraged her, and helped her feel “like it was worth it all” at a time when her “self-esteem ...was in the dirt.” After an unplanned first pregnancy, Isabela had had to leave her job cleaning

houses because of her second pregnancy, about a year before our interview. The fact that she did not feel like she could do anything had made her feel bad - so bad that the advocate had helped her get therapy for depression. What's more, her husband was gravely ill. He needed multiple life-saving surgeries at a hospital more than an hour's drive from their home near La Clínica. Faced with the possibility of losing her husband at the same time that she was carrying their second child, she described how her advocate, sister, and brother-in-law helped her during a time when she felt like “the world was closing” around her.

Now that her husband’s health had improved and her children were growing up, Isabela wanted to “bring [herself] up in this country and move forward without any fear of anything,” so that her kids will feel “proud” of her one day. This meant setting everyday goals: learning English, enrolling her daughter in swimming at the local YMCA, and, eventually, returning to work cleaning houses. It was difficult work, she explained, but important too, and she always enjoyed it. After several years of hardship, she was hopeful about the future: she and her family were moving forward. Isabela’s story points in two important directions: first, towards another point of durability in the grey market, the Programa de las Promotoras, and second, towards social reproduction as a key source of value for women in the grey market.

The Programa de las Promotoras

The Programa de las Promotoras is a home visiting program for pregnant women and mothers at one of the many partner agencies with which La Clínica staff work. As one of the program staff members explained to me during an interview, lay health promoters visit the houses of women who are pregnant with their first baby or who have high-risk pregnancies. It

was widely known among the women that I interviewed, and the mention of the program's name brought smiles to the faces of the women who had participated.

In addition to providing emotional support - “áximo” - to pregnant women, these advocates help women apply for Medicaid, Emergency Medical Assistance, and CHIP¹⁵ for their babies, once they are born. The agency also offers programs for mothers who are not enrolled in or who are not eligible for the Promotoras program, like parenting classes and childbirth education. The program enrolls women as early in pregnancy as possible and then works with them through the baby’s second birthday. La Clínica is the program’s largest source of official referrals. Other clients come to the program via word-of-mouth. Many of the women that I interviewed at La Clínica had gone through this program or were currently enrolled. Women who were no longer eligible - because they were no longer first-time mothers, for example, and did not have any qualifying risk factors during their current pregnancies - described trying to re-enroll in the program and their disappointment when they could not. Although the program’s main goal is to lower the county’s infant mortality rate, it is a key source of support for pregnant women at La Clínica - both in terms of emotional support and practical assistance in obtaining health insurance coverage.

Like other points of durability in the safety net, the Promotoras program accounts for social and medical forms of vulnerability in its own enrollment criteria - namely, first time motherhood and medical risks to a mother or baby during pregnancy. And as with other points of durability, one key way to reach program goals - in this case, lowering the infant mortality rate - is to help pregnant women gain entry to the healthcare marketplace, again by foregrounding

¹⁵ The Children’s Health Insurance Program (CHIP) is another aspect of the Pennsylvania state Medicaid program. Children whose families meet income guidelines are eligible for health insurance through CHIP - no medical debility is necessary, as is the case for most “buckets” of adult eligibility. As well, all children born in the U.S. (as

various forms of social and medical debility. At Programa de las Promotoras, program staff must work hard, often in collaboration with La Clínica staff, to help women gain entry into the grey market through Medicaid applications, applications for Emergency Medical Assistance, and CHIP applications for their children once they are born.

As one of the program staff members explained, the system works insofar as women are often able to get health insurance coverage, either through Medicaid or Emergency Medical Assistance, and they are typically able to enroll clients' babies in CHIP too. Yet, these applications take time and constant vigilance. The health advocate must help a woman gather reams of paperwork documenting, for example, a woman's income, even if she is an undocumented immigrant. This entails having a woman's employer document that she has been paying her, even if she is undocumented and the act of employing her is itself illegal. Often, in fact, women's employers are afraid to attest to having hired them. The more forms of documentation a woman has, the stronger that woman's application for insurance coverage. However, immigrant clients and especially undocumented clients are reluctant to collect such traces of their unauthorized status in the first place, let alone hand such proof of such status over to state officials.¹⁶

In addition, to build a strong case for eligibility, women must typically collect all of their own medical records to help make the case that they are eligible for Medicaid or Emergency Medical Assistance. Because of federal privacy laws, hospitals, clinics (including La Clínica) and programs like the Programa de las Promotoras are highly restricted in what kinds of medical information they can share. Thus, women must often go door to door to collect their own health records in order to have a completed Medicaid or Emergency Medical Assistance application.

were the children of the pregnant women that I interviewed) are U.S. citizens, and thus they are eligible for programs like CHIP even if their mothers are undocumented immigrants.

This, in turn, requires not just extra work on the part of the pregnant woman to obtain all of her records, but also extra support from her advocate and program staff. Just as at La Clínica, maintaining these points of durability in the safety net requires a delicate choreography.

Safety Net(work)s

One night towards the end of my fieldwork at La Clínica, one of the staff members asked if I had been hearing the kinds of things I had expected to hear from the patients I was interviewing. I replied that I had been hearing a lot more about fear, and a lot less about problems with Medicaid and Emergency Medical Assistance, than I had expected to. She nodded and suggested this was because fewer women were getting approved these days. As she explained later, in an interview over pizza the following spring, the Affordable Care Act puts another safety net under the existing safety net. But it does not do away with the United States' third party payer insurance system, and it does not make healthcare a right. Despite the considerable scientific gains in women's healthcare research over the past thirty years, and the resolution of southeastern Pennsylvania's "childbirth crisis," she had little expectation that the U.S. would ever see the low maternal mortality rates in other countries because so many women are still excluded from the healthcare market (Bishop 2006, Hallowell 2013).

As Honoria and Isabela's cases show, the terms of the Emergency Medical Assistance program reveal 'the safety net' to be a network of people and institutions. Clinicians, patients, and advocates hang on to each other in the collective work of trying to get the care that a patient needs. In so doing, they leverage particular claims of emergency at particular points in the overlapping local, state, and federal bureaucracies. This creates points of relative durability in which providers and advocates can leverage these claims to make obscure provisions of the

¹⁶ [Double check details against interview transcripts]

Pennsylvania state welfare code and federal law work for particular cases, while others fall through, leaving their futures uncertain. Such points of durability also reveal tensions within the remnants of the welfare state – such programs protect the financial welfare of individuals and hospitals, while situating the state as the insurer of “last resort” (Department of Public Welfare 2013, 4). These balancing acts highlight the “bounded optimality” of the grey market (Brown et. al. 2013; Hallowell 2013).

Value and Social Reproduction [cut for space]

Isabela’s story (continued) and Barbara’s story – concerns about fear/isolation, lacking support, needing support, childcare. Finding support among family members/friends in a bad economy. Quote from Dolores about how if you are Mexican, it is difficult to find support.

Conclusion

As we have seen, pregnant women seeking prenatal care must have some kind of currency to enter healthcare markets. For women at Medical Center, this is typically a Medicaid card. Once a woman’s Medicaid policy is in place, she has access to some of the highest quality care in the world. She can deliver at nationally recognized hospitals. If she needs high-risk care, she may see a leading maternal fetal medicine specialist. She has 24-hour access to a nurse or on-call physician, and will only pay a nominal fee if she needs to go to an emergency room.

For women at La Clínica, the currency they use may be a literal cash payment. The cost of their care is offset, at least partially, by one of La Clínica’s many grants. Although documented immigrants and U.S. citizens at this clinic may be eligible for Medicaid like the women at Medical Center, the many undocumented immigrant women here rely on Emergency

Medical Assistance when they need high risk obstetrical care or other types of specialist care and their cash runs out or a specialist does not take cash.

In both cases, women must often rely on legible forms of sociomedical debility to even acquire these forms of currency in the first place. In the case of the Pennsylvania state Medicaid program, this typically means that women are both pregnant and very low-income. Although the Affordable Care Act intended to shift the requirements for Medicaid eligibility from pregnant and very low-income to simply low-income, in Pennsylvania we have seen a doubling down on the vulnerability requirement in the Healthy Pennsylvania Plan discussed in Part 1 of this chapter. Thus, these programs cast pregnancy and poverty as forms of vulnerability that is itself a necessary precondition for gaining currency - in the form of a Medicaid card or approved Emergency Medical Assistance application - usable in the grey economy of U.S. healthcare.

For women applying for Emergency Medical Assistance, eligibility typically means that they are pregnant, very low-income, and also very sick. And because undocumented people have been systematically cut out of the Affordable Care Act, including buying insurance at full freight on the new insurance exchanges, the “pregnant + very poor + very sick” formula for market participation beyond the level of the primary care clinic seems unlikely to change in the near future. For women like Evelyn, Honoria, Isabela and the thousands of others who receive care at Medical Center and La Clínica every year, this means that they must continue to leverage pregnancy, poverty, and in some cases serious illness as forms of currency in the grey market of U.S. healthcare. Without such currency, even cash payments may not be accepted at a provider’s office, as there is no guarantee that any one provider will accept cash or a given insurance policy.

As we saw at Medical Center and La Clínica, staff members work extraordinarily hard to help their patients get and maintain these toe-holds into the grey market. But for most women,

this entree is strictly conditional. Once a woman is discharged from the hospital, once the Emergency Medical Condition is resolved, or once her pregnancy is over, the coverage ends and she is once again uninsured, left to pay for any care she may need out of pocket. And those payments can be extraordinary. With expenses going up, as Honoria described, the price of even just two trips to the emergency room can become an invisible emergency during pregnancy.

Yet, as these women's descriptions of their pregnancies show, 'real' vulnerability comes from surrounding yourself with the wrong people, losing a job, and ever-increasing expenses. Value, on the other hand, emerges from social support and the work that enables social reproduction. For Evelyn, this meant surrounding herself with people who value life as she imagined a house for herself and her kids with a two-car garage. For Isabela, this meant leaning on a Promotora who helped her feel like all that she was going through was "worth it," until she could begin to think about the future: returning to work, learning English, and enrolling her daughter in swimming classes. These everyday acts of actual and imagined social reproduction - in other words, the things that enable endurance (Cattelino 2008, Povinelli 2011) – are the sources of value that matter.

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