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Revaluating genetic causation:

Biology, economy, and kinship in Dakar, Senegal

ABSTRACT

In this article, I call for enlarging the conceptual terrain for viewing local biological expressions of illness. To date, a specific DNA sequence pattern, called “the Senegalese sickle cell haplotype,” has enjoyed extraordinary purchase on explanations for why Senegalese people may live with a “milder” form of sickle cell anemia when compared with other African populations. I argue, however, that “mild sickle cell” in Senegal emerges as a lived construct through a constitutive bond of biology, economy, and kinship. I show how patients’ enactments of biological difference are situated within larger informal economies and North–South donor priorities for health. In the absence of state funding to address patients’ needs, Senegalese sicklers create networks of care, health, and normalcy by drawing on Wolof idioms of “shared blood” that come to life in ways beyond metaphor. Their biosocial kinships result in therapeutic economies that restructure valuations of sickle cell despite serious medical constraints in this global context. [*biosociality, genetic causation, informal economies, kinship, Senegal, sickle cell, therapeutic economies*]

Reality is not a crucial appearance underlying the rest. It is the framework of relations with which all appearances tally.

—Claude Merleau-Ponty, *Phenomenology of Perception*

In 1984, long before everyday Americans became interested in studies of human variation, now popularized by numerous ancestry testing companies, televised documentaries on genetic “roots,” and a general media fascination with genetic genealogy, a team of mostly French geneticists came up with one of the first iterations of a genetic probe that could track one’s “origins” to peoples in modern-day Africa. This ancestral placement was not just for anyone, however: The focus of the study centered on people of African descent with sickle cell anemia. While examining the chromosomal region where the sickle cell mutation resides in a patient sample of Senegalese, Beninois, and Central African Republic research subjects, the geneticists in question noted that distinct DNA sequence patterns existed for the majority of people within each defined group (Pagnier et al. 1984).¹ These kinds of patterns, in the scientific parlance that is becoming less arcane to the increasing number of people who are now testing for genetic ancestry, are called “haplotypes.” The idea of “African” sickle cell haplotype differences, in 1984, was, however, never really intended to provide a tool for people to trace ancestry, although the study authors mused about this possibility.² Instead, these researchers, mostly working in Paris with collaborators in the African locales from which the samples came, were driven by a curiosity about variability in sickle cell illness expression. Specifically, they were attempting to explain medical observations that people with the disease living in one part of the continent, namely, Senegal, appeared to be less affected by sickle cell symptoms than people living elsewhere. The geneticists hypothesized that the many perceived differences in sickle cell expression could be attributed to genetic effects that were usually inherited along with the sickle cell gene (Pagnier et al. 1984:1773).

Subsequently, this same team labeled sickle cell in Senegal “mild” because Senegalese people appeared to have less frequent hallmark symptoms of the disease, notably, fewer painful “sickle cell crises” (Labie et al. 1985).³ Senegalese sicklers,⁴ they pointed out, also often had slightly increased levels of healthy fetal hemoglobin (HbF), the form all people are born with but lose after the first few months of life. This healthy normal fetal blood protein was thought to offset some of the negative effects of the “adult” sickle variant (hemoglobin S, or HbS). This slight biological trend in Senegalese bodies was associated thereafter with the genetic sequence for sickle hemoglobin, which then became doubly associated with better illness experiences on the part of Senegalese people with sickle cell disease.

The link between a population-based genetic marker, such as “the Senegalese haplotype,” and sickle cell severity has persisted for many biomedical professionals who work on the disease in Senegal, in its former colonial power, France, and in the United States (Diop et al. 1999; Garner et al. 2002; Nagel et al. 1991; Powars and Hiti 1993). This is not to say that sickle cell specialists with a range of scientific backgrounds do not concede that multiple factors might influence disease expression. Indeed, they do, but for most scientists such factors are limited to “genetic” interactions (for reviews, see Lettre et al. 2008; Steinberg 2004). Yet what other kinds of actual behavioral, cultural, and even ethical “interactions” and conditions might explain the Senegalese genetic exceptionalism that many patients and doctors in Senegal have come to accept?

The idea that “the Senegalese” as a population enjoy a specifically light form of sickle cell anemia is particularly interesting for its newness. This is not to say that the older optic for viewing human distinction through sickle cell in West Africa does not warrant attention. Studies of sickle hemoglobin and its frequencies in specific populations in Senegal’s capital of Dakar that took place before 1960, when French colonization ended, predated modern genetic techniques and were based on blood protein analyses that detected sickling potential in blood donors, army recruits, and schoolchildren (Pales et al. 1954; Pales and Linhard 1952). From the results of these studies, colonial researchers concluded that Senegalese with sickle cell were anything but a singular, unified population entity. In the colonial thinking of the 1950s, subjects were tested and classed by their African “race” or “subrace.” Such an emphasis on human difference permitted French colonial medics and anthropologists to hypothesize that hemoglobin S might serve as the serological “proof” that Senegalese ethnic groups in Dakar could be categorized as biologically distinct—one from the other (Bonnecase 2009:164–165; Fullwiley 2004a:248–249). By contrast, today it seems that the Senegalese nation-state provides the conceptual boundary around which human distinction might be drawn. In this vision, all peoples within this bound-

ary, despite their self-descriptors of finer magnitude, are lumped as genetically “Senegalese” when it comes to their hemoglobin S.

New frameworks of relations for reevaluating genetic causation

Increasingly, genomic information appears to be changing scientific, societal, and sometimes national conceptions of human groupings (Abu El-Haj 2007; Comaroff and Comaroff 2009; Pálsson 2007; Rabinow 1999; Reardon 2005). Accordingly, medical anthropologists have taken up new field sites where genetic knowledge is being produced. One key finding from this anthropology of science is that a slippage occurs when geneticists observe biological “outcomes” and assume, as a first response, that illness effects should be attributed to distinct genetic sequences that populations demarcated for study purposes possess—albeit at different frequencies (Fullwiley 2008; Lakoff 2005; Lock 2005; Montoya 2007). In this article, I examine how overloading disease severity, or, in the Senegalese sickle cell case, “mildness,” as the effect of genetic sequence variation may miss how such “physiological” facts rely on cultural contexts for their sense. I argue that conceiving of a less symptomatic form of disease in solely molecular terms overlooks the complex congeries of care and economies of shared pain that influence disease experiences and individuals’ biological expressions of illness.

By engaging cultural frameworks of relations, notably, of kin ties, and social as well as economic safety nets that mitigate sickle cell suffering in Dakar, I hope to enlarge the conceptual terrain of how geneticists, anthropologists, and the increasing number of individuals undergoing personal genetic testing view causal factors for varied disease manifestations. Because causation is increasingly conceived in molecular terms, the notion of “population,” for the purposes of indexing a genetic effect, seldom includes analyses of the social relations, familial bonds, economic constraints, and survival strategies of the group in question. By analyzing local Senegalese discursive practices that name a form of HbSS sickle cell “mild,” I bring affects—which extend beyond emotions to patients’ shared sentiments and family ties that inspire health—into this picture. Put simply, people’s moral concerns of caring for the other, of going to incredible lengths to make family and loved ones live in health, is the human, intersubjective substrate that undergirds an experience of alleviated sickle cell stress, both bodily and socially, in Dakar today. I emphasize that affect structures people’s actions of *entraide*, or mutual care through solidarity.

Phenomenologically speaking, a “reality” of sickle cell mildness in Dakar is the biosocial framework of relations with which health appearances seem to tally. Reality is not a truth to be excavated, if only the social analyst could dig

deep enough. Rather, it is made through care practices, contingency, and social engagements in which human actions contribute to and partially determine life possibilities.

Biosociality in Dakar

As a disease “of the blood” that runs in families and that is also a societal issue, sickle cell in Dakar lends itself to expressions of kinship and social bonds that go beyond metaphor. People enact “living well” with sickle cell through pragmatic relations with others who, as I describe below, “share their sickling blood.” This happens through specific forms of “biosociality” that extend beyond the discrete referent of genetic material proper, which, as Paul Rabinow (1999) has shown, in other contexts might animate hopes for national projects of patrimony based on passions about DNA deemed sacred. The ways that people live well with this disease in Dakar also expand the usual reading of biosociality as the biopolitical mobilization of persons and groups around precise biomarkers, notably, some mutation of “the gene” one shares with strangers (Rabinow 1996:102). Although taken for granted in places like North America, such self-sovereignty quests, rooted in individual freedom and reifications of what secular moderns consider the deep core of their identity, are not the norm in every contemporary global setting. Senegal, a developing country with health expenditures per capita that equal what might be dispensed in the United States on a single prescription, is not a place where discourses of autonomy and “choice” eagerly prevail. Life with any chronic disease in Dakar does not readily lend itself to the “peculiar persuasion of bioethics” that concern European and North American “individualized issues” (Rose 2007:31). Nor do people with sickle cell in Dakar freely share the possibility that Nikolas Rose optimistically offers those in the global North: that “biology is not destiny but opportunity” (2007:51). As Annemarie Mol observes, such advanced liberal ideas of bodily mastery hide what it would cost to reshape the world in such a way that “situations of choice” (2008:80) might somehow be otherwise.

In people’s biosocial enactments of Senegalese “mild” sickle cell anemia that I present here, opportunity is bound by structural conditions of countrywide poverty.⁵ It also takes place within a state system that has only just recently recognized the disease as worthy of public discourse. Yet, as Mamadou Seck, the president of the Senegalese National Assembly, told me in a March 2010 interview, “Parliamentarians are now debating how to carefully institute genetic testing to prevent people with the trait from marrying each other.” He added, “This is our goal, and we realize that it might be sensitive [*délicat*].” Although Seck put his finger on the pulse of the problem, or the predicament of directing an ethics from above that would serve to separate sicklers in reproductive population terms, he has yet to real-

ize that this pulse transmits the lifeblood of a much larger body. At base, individuals like Seck who make up the state have yet to see that it is precisely people’s biosocial linkages (and sometimes their flirtations with marriage) that render thick the substance that makes mild sickle cell anemia in Senegal a viable reality at all. This substance, shared blood, materializes through a biosocial ethic of *entraide* that operates among people with the disease. A closer look into sicklers’ mutual forms of care that establish possibilities for their normalcy and health begins to render transparent the opaque black box of the Senegalese sickle cell genetic haplotype and its accounting of “mild disease” in molecular terms.

As the forgoing suggests, it is people’s collective affects and actions that anchor life on the ground—the soil where sickle cell biology was once “mapped” in the molecular genetic sense. Margaret Lock has brought anthropologists’ attention to historical and global forces that result in distinct illness expressions in people in different geographical settings, what she has called “local biologies” (1993:38–39; Lock and Nguyen 2010:90–92). Drawing from Lock’s useful analytic, I maintain that we are also increasingly witnessing a phenomenon of *localized* biologies. A double entendre, my superadded emphasis on Lock’s term refers to localization in the sense of detailing chromosomal regions as well as the scientific efforts I described in the opening paragraphs: projects that make political territory fructify the meaning of DNA garnered from bodies in what are now African postcolonial nation-states.

Recognizing how biology becomes localized enables better understanding of how local biologies work, in this case, how sickle cell biology in Senegal is indistinguishable from the material dimension of kinship, shared blood, and therapeutic economies in which people distribute pain through relations of support with affected others. In establishing their bonds, sicklers often draw from biomedical knowledge of their genetic disease while they also enlarge the conceptual field of what can be attributed to genetics. At stake for us, as anthropologists, is our ability to draw on our intimate knowledge of how the people with whom we work actually live so we might repopulate the terrains on which biological objects have been localized, often, paradoxically, in isolation from life on the ground. It is with this idea in mind that I make the closed scientific concept of “the Senegalese haplotype” openly recognize its debt to the cultural actors who make “mild” sickle cell anemia cohere as a bodily outcome in the first place.

Acts to improve life that I witnessed among people affected by sickle cell in Dakar include efforts to share pain, gift material goods, and establish value—more precisely, the value of life itself, even a burdensome, costly one—in an economic setting where biomedical scarcity perdures. This valuing starts with people’s self-injunctions to “live well” with sickle cell—injunctions that also frame subjective

expressions of illness that accent health more than disease. Doctors, in their everyday interactions with patients, also prefer this emphasis on health because a tallied reality of mild sickle cell frees them from anxieties of not being able to import the frontline therapies used for the disease in France, where they have many professional ties. That Senegal is “blessed” with mild sickle cell anemia thus not only “saves patients,” as one practitioner told me, but also saves health professionals “the expense of having to do so.” It is in this context that many people—both patients and biomedical practitioners—describe sickle cell care and survival as “making do” [*góor góorlu*],⁶ or “managing” less than ideal conditions.⁷ Senegalese sickle cell biology does not cohere without the material constraints that condition sicklers’ expressions of illness. In other words, “mild sickle cell” may be correlated with a series of genetic markers, but the lived disease that people conjure through subjective and intersubjective feelings of health has entrenched biological roots in economic scarcity.

This general scarcity of resources is furthermore rearticulated by the state Health Ministry’s own pressure to triage illnesses in a context where postcolonial North–South donor dynamics direct the state to invest in UN and WHO global health priorities, such as HIV/AIDS, malaria, and maternal–child health (Fullwiley 2004b:158–159). This leads to a state neglect of widespread diseases like sickle cell, which, given current testing technologies and cultural understandings of the sickle cell trait, implicates those who possess one copy of the gene (referred to as “benign carriers” in the United States) as well as those who carry two (HbSS sicklers, in whom the illness is usually expressed; see Fullwiley 2006:422–424). In other words, in many people’s view, often including biomedical practitioners, sickle cell is seen to affect at least ten percent of the Senegalese population.⁸ For sickle cell researchers and disease specialists in Dakar, as well as for laypeople, the fact that Senegal’s state powers have only recently articulated sickle cell disease as a health problem of concern has yielded an effect that I have called “discriminate biopower” (Fullwiley 2004b). Here, the state’s attention to managing life and health has been heavily focused on problems that have donor-country-aid development (*coopération*) funding streams, all the while sidestepping afflictions like sickle cell (Fullwiley 2004b:160–161). Senegal finally established a National Program for Sickle Cell Disease in 2005, but very few funds have actually materialized for it. Since then, a marked change in sickle cell public visibility seems to have done little in the way of creating patient health care resources on the ground.

After much solicitation from the Paris-based sickle cell disease network *l’Organisation internationale de lutte contre la drépanocytose* (OILD),⁹ Senegal’s first lady, Mme. Viviane Wade, made sickle cell one of the health talking points of her NGO, *Association éducation santé*, beginning in 2005. In 2008, she launched a “public plea” (*un plaidoyer*) for

sickle cell consciousness-raising in the National Assembly, the Health Ministry, and, strangely, the Ministry of Transportation. Because of these efforts, her NGO has been the recipient of monies from the National Assembly and from the Transportation Ministry, a small percentage of which have been used for “sickle cell awareness.”¹⁰ This cash flow from the state (or from specific sectors that could free up a portion of their budgets for an education drive) to the first lady happens in a context where non-health sector divisions of government do not want to be seen as donating to a single disease but whose members, it must be admitted, may want to curry favor with the first lady. Undoubtedly, donating to an NGO run by the first lady for the purpose of “helping those with sickle cell,” rather than putting pressure on the Health Ministry to allocate funds for the disease, actually undermines the national sickle cell program—which has benefited from far less state financing than has Mme. Wade’s NGO. Not surprisingly, the Health Ministry has not yet granted the yearly funds it promised to the national program since its inception.¹¹

In a 2010 interview, Abdou Fall, the current vice president of the Senegalese National Assembly, who was Senegal’s minister of health from 2005 until 2007, clearly indicated that the state is still deciding whether sickle cell is a worthy priority. In Fall’s top-down vision, “the first lady’s public plea for awareness was *the* action that made the government conscious about the disease at all.” For him, “It is state leaders who must, first of all, make the problem one of public concern, then technicians within medicine, or civil groups like the sickle cell association can make their needs heard.” Mme. Wade’s political plea has done little to usher in resources for testing equipment in care centers or for state subsidies to offset patients’ financial responsibility for hospitalizations—the costs of which have been detailed by local doctors in a document they refer to as *le plan stratégique*. According to Fall, these items “still need to be approved.” A handful of country specialists submitted their strategic plan addressing these issues to the Office of Chronic and Non-Communicable Diseases within the Health Ministry in 2008. Two years later it still awaits approval. To the frustration of those charged with implementing the national program, Fall mused that “this approval would likely come with more consciousness raising.” He also emphasized that the chronic and noncommunicable diseases office “deals with much more than sickle cell,” intimating that, in practice, sickle cell shares funds donated from *la Coopération européenne* with an increasing number of chronic problems, specifically framed as such, a trend that began under his watch.¹² In this competition, sickle cell has not fared well.

The majority of the funds that the first lady’s NGO receives go to needed programs for HIV/AIDS, malaria, sleeping sickness, malnutrition, children’s education, and hospital projects in rural zones, but not to sickle cell.

Nonetheless, it has to be reiterated that Mme. Wade's nominal sponsorship of sickle cell disease has finally broadcast the issue on radio airwaves, on public television, and in the national press. Wade now refers to herself as the "godmother" [*la marraine*] of Senegal's "children" with this genetic disorder. She is the first to admit, however, that her godmother gifting capacity is limited in a state that cannot afford "the costs of sickle cell" and all of the sick under its tutelage. Her hope is that the UN will take interest so that international funds to the state might follow.¹³

By considering the effects of economic triaging and local competition among diseases for international and national funding sources, one gains deeper insight into local attitudes, investments, and valuations of the Senegalese haplotype and its charge of assuring a better than expected disease outcome in Dakar. It is important to foreground the economic health setting in which Senegalese sickle cell lives because, as Elizabeth Povinelli (2006) points out, concepts that obscure the processes of their origins, like the Senegalese haplotype, often retroactively constitute the importance of individualized, nationalized, and now geneticized characteristics. The visible face of such lived constructs often compromises people's ability to see the intimate relations and immanent global interdependencies that make any identity, economy, destiny, or biological opportunity materially possible in the first place (Povinelli 2006:18–25; see also Ferguson 2006:22–23). This is not to negate the reality of mild sickle cell in Senegal. It is simply to begin to situate it in an economically cleaved world.

Given how Dakar's public health spending has traditionally passed over the disease, many active patients are in a bind over how far to take their idioms of identity when it comes to constructing an image of themselves as both "children" of the state and "a family" unto themselves. They live a strange configuration of "cultural intimacy" (Herzfeld 2005:50), in which their rejection of official norms is tentative, because the idea of preventing the disease that Seck and the National Assembly hope to make stick must also still find its legs. People with sickle cell are still trying to figure out how to deal with a mode of state management that would compromise their hopes for simply being with their disease as well as living with, dating, marrying, and mutually supporting others who have it. As will become clear, living with sickle cell in the Senegalese nation-state is defined by a biopolitics in which these internal dilemmas and questions about how to go forward define people's aspirations for normalcy through what Rabinow, in his engagement with Niklas Luhmann, calls "provisional foresight" (2008:60). Here the present (life as one knows it) and the future (probabilities that cannot be truly known) are two sides of a "respectable uncertainty" in which one must incessantly try to correct and adjust to a reality that comes to be other than what was at first expected (Rabinow 2008:60). In other words, personal action does not follow a moral clo-

sure where agreed-on norms are socially and biologically performed. Engagements of care themselves are morally shared activities. The human commitment to others, even as one is still figuring out the moral complexities of his or her interventions, is a defining act of solidarity and practical assistance (Kleinman 2006:78–79). In most cases, such moral actions also undergird morale, as they require people to possess wells of tenacity, perseverance, and adaptability (Mol 2008:78–79).

It must be acknowledged that in Dakar, hopes for the future, and people's adjustments to reality, are, nonetheless, exerted through a morality that is often animated by despair. Senegal is a small country where abuses of power have engendered extensive and damaging criticism from local NGOs and journalists.¹⁴ Nevertheless, the nation is considered relatively stable and its president, Abdoulaye Wade, has a reputation as an "apostle for African democracy," an idea based largely on the country's ethnic and religious tolerance (Gellar 2005:157, 161–165; cf. Beck 2008:228–229).¹⁵ Yet, for many everyday citizens, there is a constant sense that things must change, especially with regard to the economy and life chances. This desperation became all too palpable when thousands of unemployed Senegalese took to the high seas in their fishing canoes, departing at record numbers in 2006. Many of these boats capsized, and people died by drowning and from dehydration as they proclaimed, "Barça or Barsax" [Barcelona or the hereafter]. This is a painful example of "opportunity"—offered to the unemployed by local *passeurs* (smugglers) and made intelligible by disparate global economies—that is less about *chance* (Fr. luck) than about avenues of circumscribed constraint. Women, mainly mothers who lost their sons at sea, channeled their emotions and pragmatically created a collective to end this form of economic migration and the literal death of their kin by economic pressures to flee at all cost (Bangré 2006).¹⁶ Political associations that bring awareness to issues in which life, kinship, and economy meet are therefore clearly not limited to sickle cell in Dakar but may be manifestations of a larger societal reflex. My position is that all such movements require ethnographic attention to how people's chances for survival become redistributed, sometimes consequentially, because of civic and personal collective actions that allow them to intervene when the state and the larger international community are slow to engage or commit with controls that overlook structures that potentially perpetuate more suffering.¹⁷

What is particular about active sickle cell patients is that their pragmatic forms of intersubjective care allow them to enact biosocial exchanges, from which they extract therapeutic value. This happens when people with the disease find ways to mutually improve the lives, bodies, and biologies of themselves and others—lives that come to constitute a reality of sickle cell success more broadly. In other words, taken relationally, people with this disease in Dakar

create safety nets of support for health that continue to produce the effect of a geographically located genetic population that has been “blessed” with mild sickle cell anemia.¹⁸ Taking seriously the work of their collective ties, both formal and informal, allows one not only to personalize the effects of economy but also to denaturalize the effects of biology.

This is the larger context where sicklers refer to deep “feelings” of wanting to intervene on the conditions of biologically unrelated others and then act on these impulses to do so. These actions overlie a social matrix where many also find their well-being through more traditional forms of family, and where individuals affectively embody the investment in their health that another’s care and economic sacrifice have underwritten for their survival. Examples of these human(e) moral configurations of affective attachment take varied forms, as the cases in the second half of this article demonstrate. Prior to considering them, however, I show the ease with which people wield the materiality of “shared blood” before then reviewing anthropological reflections on kinship and the social life of informal economies in Africa. This background provides the framework for understanding how mild sickle cell anemia becomes biosocially structured through contingency and networks of informal therapeutic economies in Dakar. It also makes clear that this case is far from one of “biological citizenship,” in which the sick in precarious global settings enter into illness categories to obtain state health care benefits (Koch 2006; Petryna 2002). Even such compromised social security is not an option for sicklers in this part of Africa. A prominent disease specialist drove home this point as he told me flatly, “When it comes to sickle cell, the problem is that we have a no state. We have a country, but we have no state.” The “country” is of course the terrain on which I started, the ground where the population’s genes may be culled, but, more importantly, where active patients and others live together to offset the most nefarious manifestations that sickle cell anemia might pose.

Biosocial ethics of care

Maguëye Ndiaye, the current president of the *Association sénégalaise de drépanocytose* (Senegalese Sickle Cell Disease Association; ASD), clutched his thin, albeit “healthy,” sickle cell body and rocked forward to emphasize the point he was about to make. “Why can’t I just take his pain? It’s frustrating.” He was referring to a small boy he had just met at Albert Royer Children’s Hospital in Dakar. The boy’s mother had heard Maguëye speak publicly about his own disease during a recent event aired on radio. She ran into him at the hospital when he was trying to convince a social worker to help a patient. The boy’s mother congratulated him on his “achievement”—not convincing the social worker but “living to the age of 31.” She asked him to come visit her son, who might see himself in Maguëye, a healthy adult living with his same blood disease. The boy in question appar-

ently feared that he would never grow up because he was a *drépano* (Fr. sickler). Maguëye continued to recount the story and his emotional dilemma when faced with the child in pain.

He couldn’t handle the crisis . . . Since I’m rarely sick, I often visit people at the hospital. In my mind, I try to take their pain, to share it in some way. If only people could know that they are not suffering alone. I think about this a lot. I wonder—if only there was some way that you could actually take someone else’s pain for a while . . . If you could just pull it out from them, and take it on, I would. People don’t think about this, but, why not? . . . just take his pain and let him rest.

Maguëye also recounted the stories of his own doctor looking out for him when he could not afford to buy medications, saying, “It’s like big brother–little brother.” With such an outlook, he developed a discourse of “sickle cell” familial solidarity through idioms of shared blood. “We have the same sickle blood running through our veins,” he would tell other sicklers, “therefore, we are family.” Maguëye easily drew on the Wolof inclusive term for family, *nu bokk deret* (we share blood) or, alternatively, *sama bokk la* (she or he is shared, she or he is my relative). Such biosocial relations of caring, in different configurations, allowed people to find a certain naturalness of affinity through kin idioms that whittled down clear distinctions between subject and object, personal “ownership” of suffering and disease, and self as separate from the other in pain.

On a broader level, Maguëye began to imagine sicklers’ potential for therapeutic biosociality with regard to formal economic health resources as well. Still drawing on idioms of shared blood, now to pool monies for the possibility of aid when needed, in 2009 he pursued creating a hybrid entity he called a “sickle cell health insurance–mutual savings–microcredit plan.” For Maguëye, ASD members’ pooled savings could create a base for “microcredit” loans that would allow people to start business projects, obtain required care, or afford occasional hospitalizations without putting their families into debt. Although the initial capital posed a problem, he set out to find interested pharmacists who might offer ASD adherents discounted medications. His first benefactor was, not surprisingly, someone who had sickle cell in his family.

Kinship understandings and varied forms of biosocial affinities are a crucial source of both physical and cultural practices of survival in Senegal more broadly. It is through such relations that sicklers in Dakar are able to reduce their disease burden, in some cases, and experience their sickle cell status as a kind of existential normalcy, in others. Yet kinship connections, like genetic data points, must be seen through their constitutive parts. That is, the outward, nominal understanding of kinship structures—as specific kinds of human ties—are filled with elements that

are seemingly distinct from European or North American commonplace understandings of biological bonds, in this case building a disease support structure as a political need or gifting medical care as an economic good. Too often economic resources invested in making someone who is suffering live better do not explicitly surface in terminologies of relatedness.

The work that the bond, or chain, of kinship achieves, as a form of relatedness that is not at all confined to birth-family blood ties, very much parallels Michel Foucault's idea of "governmentality." It is not accidental that Foucault writes, "Power relations, governmentality, the government of the self and of others, and the relationship of the self to self constitute a chain, a thread" (2004:252). He further elaborates that it is around these notions that "questions of politics" and "questions of ethics" connect (Foucault 2004:252). This ethical work, rooted in relationships, happens at a level below the "state" proper, at the level of people with similar conditions, families, comrades, and loved ones.

Kinship and economy

Anthropologists have long been interested in how biology, economy, necessary goods, and relatedness fuse in particular ways across a range of diverse societal settings. As Marilyn Strathern demonstrated in her seminal article "Kinship and Economy: Constitutive Orders of a Provisional Kind" (1985), the ordering of kin connectedness encompasses economic exchanges as relations themselves, in which both relatedness (i.e., marriage) and interpersonal ways of relating (exchange of goods) cross over. In this crossover, kinship systems often function through abstractions as, for instance, symbols of connectedness are enacted through the delivery of prized goods, such as cattle, power, wives, and daughters, to one party on the part of the other (Comaroff 1980:38; Hutchinson 1996; Strathern 1985:205). Strathern, borrowing from John Comaroff, uses the term *constitutive order* to signal the singularity of kinship as a particular institution in which seemingly disparate elements, such as things and persons connected to and also exchanged by families, merge. She then backtracks heuristically to say that these "separations" may never actually have been distinguished in the first place for many people around the globe (Strathern 1985:201). Here one of Strathern's keenest insights bears repeating: In many cases, "anthropological analysis establishes itself only through distinctions"—such as kinship and economy—"even when it wishes to collapse them" (Strathern 1985:201; cf. Strathern 2005:91). The collapse of particular categories, or, rather, of making instances of their oneness explicit, may seem jolting at first glance. Yet Strathern and others who have revived recent anthropological interest in kinship would focus less on the "two" parts, or terms, of this relation and more on the *relation itself* (Carsten 2000; Strathern 1985:201; Strathern 2005:91). Building on this, what would

it take for anthropologists to add still other "parts," such as biological traits, or bodily expressions of genetic illness, to this relation of oneness? Clearly, kinship is often configured with ideas of biology at some level. My hope, following Sarah Franklin, is to "defamiliarize the very nature" of what it is for any phenomenon "to be strictly biological" (2001:303).

The social life of economy in Africa

When the state is not a key player in cultural and medical processes, as has been the case with sickle cell care in Senegal, its absence easily becomes a consequential target for complaint, protest, and action.¹⁹ An analysis of how sickle cell in Senegalese bodies comes to be understood as mild in the absence of state resources benefits from recent theorizing within the anthropology of economic entanglements between the global North and South. As several works on Africa have made clear, informal wealth and resource creation have become central to official state functioning (Ferguson 2006:103; Roitman 2004:19)—in the present case, to sickle cell health care functioning—where people formulate new sites of authority and health efficacy and build their own "public-political foundations" in lieu of, and in addition to, the state (Mbembe 2001:76). Taken as an aggregate, with many individuals hustling to attain the goods to secure survival, Senegalese sicklers ameliorate their prescribed fates, partake in rendering their disease "mild," and often attain adulthood despite a staggering lack of medical technology and standard interventions and resources that constitute sickle cell care in the United States and France.

Specific lessons on similar trends abound in the recent anthropology of Africa. Focusing on the ability of people to secure wealth despite their minimal resources, Julia Elyachar (2002) and Janet Roitman (2004) offer critiques of the telos of modernization, development, and growth strategies that have left the world's poorest to survive by "informal" means. They point out the failures of global market logics to incorporate impoverished nations into more equitable economic relations—through structural adjustment programs as well as, in Elyachar's work, more palatable programs to empower those in poverty through microfinance or decentralization made possible by the upsurge of NGOs. People's economic survival strategies, which at one time may have been deemed "below" or "outside of the state," are no longer formally unofficial, because they serve functions, such as governance (networks of care), and provide new forms of wealth (networks of value) that the state no longer does. Instead, various instances of what Roitman's informants have embraced as "fiscal disobedience" (not paying tax while generating their own "tax/price"²⁰) are proving to be an integral part of economic development and individual livelihood in satisfying certain basic needs and, in some cases, procuring extravagant goods that allow the official state structure its power and even varied

forms of sustenance (Elyachar 2002:500; Roitman 2004:22; also see Fassin 1992:95–97; Ferguson 2006:101–102; Guyer 2004:163–164).

The fundamental lesson of this recent anthropology is that economy must be understood broadly—perhaps in its original sense implied in the orthographic rendering *oeconomy*, from *oikos* (house) and *nomos* (norms)—with the norms that govern “the private,” the interior, the intimate sphere of human activity being crucially important for understanding how the minutiae of the everyday moves public life. This emphasis gets one beyond statistical indexes of unemployment, national income, rate of growth, and price levels. Real people and the circulation of goods important to them, wealth creation through investment in social bonds, the sociability of indebtedness and interdependency, and an extensive notion of reproduction as a kind of “futures contract,” or at least a social contract with generations to come, are all in play in Senegal. If one looks close enough, however, even more traditional economic indexes reveal the importance of the “home,” and the private interior sphere, as a wedge to manage poverty’s most debilitating effects.

Poverty in numbers

In January 2004, the Senegalese Ministry of Finance, the national Forecasting and Statistics Office, and the World Bank jointly issued a report called “La pauvreté au Sénégal: De la dévaluation de 1994 à 2001–2002” (Poverty in Senegal: From the currency devaluation of 1994 to 2001–2002). These experts optimistically pronounced that Senegalese individual household poverty rates declined from 61.4 percent in 1994 to 48.5 percent in 2001–02. When the surveyors left the domain of “household” and counted individuals, the numbers looked less impressive. In real population terms, 67.9 percent were said to be impoverished at the time of the 1994 currency devaluation implemented by the World Bank, compared with 57.1 percent in 2002. These claims and their attendant comparisons were made on the basis of Senegalese Household Surveys I and II (*Enquête sénégalaise auprès des ménages*, or ESAM, I and II, carried out in 1994–95 and 2001–02, respectively).

The “Poverty in Senegal” report recognizes the importance of methodology, acknowledging that, “the differences in poverty estimation can be a result of poverty indicator, poverty line, and poverty measure choices” (Ministère de l’Économie et des Finances et al. 2004:7). Yet it fails to discuss the discrepancies in method between the two instruments that produced these disparate numbers. It also cites another report, based on a survey of the same population sample in 2001, tellingly called “Enquête sur la perception de la pauvreté au Sénégal” (Perceptions of poverty in Senegal; Direction de la Prévision de la Statistique [DPS] et al. 2001), or EPPS. In comparison with the reported results of ESAM II, the “Perceptions” document

found that, of all urban households questioned, 73.3 percent reported that their communities were impoverished. Nearly three-quarters of the population saw themselves and those around them as worse off than simply “poor.” When surveyors queried heads of households in rural areas, the numbers in “Perceptions” climbed as high as 94 percent (DPS et al. 2001:5)—nearly the entire rural population. These figures stood in stark contrast to those in the ESAM II report, which indicated that only half of the nation’s households lived in poverty.

In the “qualitative,” more methodologically transparent “Perceptions” document, the three primary “manifestations of poverty” were ranked in order of importance as follows: “difficulty in feeding one’s family,” “lack of work,” and “not having the means to secure health care for family members.” These indicators were also among those most often described by many Senegalese sicklers and their families I met. The “Poverty in Senegal” report attributes its discrepancies with the “Perceptions” document to reliance on economic science (“objective equations”) versus subjective views (“degrees of satisfaction”) (Ministère de l’Économie et des Finances et al. 2004:5). But this judgment misses a crucial social fact underlying the numbers. Within the domain of the “household,” an experience of dire poverty may be somewhat alleviated. When individuals were asked to rate the community around them (which implies all that the state has not furnished) as separate from their own private household and kinship networks, they offered a much bleaker view.

People’s subjective experiences of what economists call “objective poverty” must be understood in the context of Senegal’s recent economic history. In 1979, Senegal was one of the first sub-Saharan African nations to enter into an IMF–World Bank structural adjustment program. A country largely dependent on the cultivation of peanuts, a monoculture crop that used 80 percent of the state’s arable land despite efforts to diversify, Senegal quickly fell short of its promises and the IMF’s payment schedule because of both a multiyear drought and a history of state care for its farmers through subsidies and loans (a laudable commitment on the part of a strapped state). In 1979, falling world market prices for peanut oil dealt another blow. Then, the rise in petroleum prices in 1979 aggravated the downward spiral of Senegal’s currency. It was against this backdrop that then prime minister Abdou Diouf approached the multilateral institutions to initiate “a policy dialogue” (Delgado and Jammeh 1991:9).

Between 1979 and 1985, through a confusing set of starts and stops, Senegal entered into various borrowing agreements. At the end of 1979, the government signed a “Medium-Term Program for Economic and Financial Adjustment,” which provided the framework for its first structural adjustment loan (SAL I). The agreement was based on neoliberal market reform: “liberalization, higher

agricultural prices, and stricter economic criteria for investment projects” (Delgado and Jammeh 1991:9). One of the first projects to be cut in the retrenchment was the costly agricultural aid structure, the *Office national de coopération et d'assistance pour le développement*, or ONCAD, on which many peanut farmers depended. Still, SAL I was abrogated because the state continued to pay subsidies to its farmers. The multilateral institutions revoked the terms of that agreement in 1983, but the country was given a second chance for reform, which was set out in the “Economic Adjustment Plan in the Medium and Long Term” (PAML), a few years later. PAML covered rules on market reorganization from 1985 to 1992 and led to SAL II in 1986. It then provided the framework for SAL III in 1987 and SAL IV in 1990. The 1990s saw a continued pattern of extended borrowing and more banking acronyms entering the picture.

During the implementation of structural adjustment, the Senegalese state was seen as undisciplined, with excessive “expenditures” for public-sector employees and farmers. The IMF then instructed the government to diversify the economy beyond peanuts and to pare down its civil services. Of consequence, these policy imperatives led to massive employment cuts in agriculture, education, and, by extension, health care, given that public university hospitals (*centres hospitalier universitaires*; CHUs) were essential for treating the population at large. In this way, Senegal began a pattern that was later repeated in many African countries that underwent structural adjustment: Declines in wages and wage employment in the formal sector not only resulted in job losses for countless individuals but also severely compromised governments’ ability to provide health education and welfare services broadly (Turshen 1999:60–61). In addition, subsidies on gasoline, imported vegetable oils, wheat, utilities, and transportation were “gradually eroded” to bring domestic prices more in line with world markets (Somerville 1991:157). For ordinary Senegalese, buying these basics posed a problem from the very start of neoliberal reform. Then, through what many economists describe as an almost natural measure to make the region’s exports more desirable, in 1994 the IMF devalued the CFA franc by half.²¹ With staid humor and cynicism, people often refer to the devaluation as a *dévaluation*, meaning to rob someone of their possessions. Senegalese saw their purchasing power radically diminished overnight. Shortly thereafter, in 1996, the Senegalese state implemented new reforms in the health sector based on user fees for services as recommended by the WHO–UNICEF-sponsored 1987 Bamako Initiative. This idea of “participatory health care” often overlooked constraints that, in practice, quickly dissolved such neoliberal ideals into a sense of diminished empowerment, rather than increased freedoms and autonomy (Foley 2008).

Finally, in 2000 Senegal was added to the unenviable list of the world’s poorest and most indebted countries.

In 2006, when the government of Senegal first promised the population public funds for a national sickle cell anemia program, the monies were immediately diverted to the agricultural sector because of “more pressing economic needs.”²² A year later, in 2007, when both sicklers and their doctors expected the funds to finally be forthcoming, the monies were redirected to cover presidential election costs.²³ Many everyday Senegalese, including several of my physician–researcher informants, were growing painfully dissatisfied with the widening gap between rich and poor due to increasing privatization of public goods, from water and electricity to “public domain” beaches.

Despite the difficulties of using the mysterious calculus of much economically based social science research to illuminate the struggles of daily life in places like West Africa, one can pull something from the numbers. Many reports on Senegal, from those published by the World Bank to profiles generated by the WHO, convey that even as the gross national income per capita for the country has nearly tripled since 2000, now at \$1,560 in “objective terms,” more than half of the Senegalese people—56.2 percent—still live on less than two dollars a day (United Nations Development Programme 2008). Focus on such an indicator should lead one to interrogate what “less than two dollars” signifies in real-life terms, given this history, including how people living on such amounts procure the means to address basic needs. Although aspects of this economic past came up in Senegalese people’s accounts of their attempts to “make do” generally, families with sickle cell roiled at how difficult it was for them to sustain the chronic cost of keeping up with clinic visits and prescriptions when they did not have money to spend. For many, the historically marked economic downturn of devaluation that Senegalese people refer to as “the crisis” [*la crise*] further compounded the present difficulty of aiding their sick kin to avoid the literal physical “crises” that are the hallmark symptom of the disease itself. Thus, people with sickle cell were habitually forced to create kin-based safety nets that blended economic and social supports, a pattern perpetuated in the creation of the sickle cell care network ASD. As I detail below, the ways that people manage care resources, both before and after they joined ASD, draw from varied forms of economy. These include manipulating bodily thresholds to reduce one’s expenditures, gifting therapeutic goods, and undertaking subjective bodily “training” that is dictated by household cash flows in the wider context of the prolonged “economic crisis” in Dakar (Antoine et al. 1995; Duruflé 1994).²⁴

Home and health economics: Training the family for healthy disease

When I first heard a Senegalese sickle cell geneticist question the relationship between the mild disease and the

Senegalese haplotype, it was in reference to a particular patient, Rokhoya Sylla.²⁵ “Perhaps she’s a statistical aberration,” Dr. Diagne, the principal hematological pediatric sickle cell specialist at Albert Royer, confided. Rokhoya had grown up under his care. When I met her shortly after her 19th birthday, she had virtually no fetal hemoglobin, the physiological marker often associated with the Senegalese haplotype, but had been “crisis free” for over five years. Diagne dubbed her his “healthiest patient.” He half joked that, in fact, she was “probably healthier than your average normal-hemoglobin-carrying Senegalese.”

It was apparent from the outset that Rokhoya was an excessively shy young woman. She only spoke to me in short sentences, about things like school and her family, and “yes, they were fine.” She did complain to me that she had recently been forced to leave high school before earning her diploma. She wanted another chance at an education and was interested to learn of any details I might have about possible support from the Rotary Club in Dakar. Why was she forced to leave school? I asked. “Because of my [Hb]SS,” she offered. The classroom had proven a dangerous environment. Although the curriculum inspired her, 65 students were crowded into a small room where “the teacher smoked long cigarettes and often closed the windows.” She told me that she “suffocated” because her red blood cells needed oxygen and that she often fell sick. Rokhoya’s parents both held “good jobs.” Her father was an accountant and her mother a university administrative assistant. She was the fifth of 12 children, and two of her older siblings were living abroad to attend college. Her parents sent a substantial portion of their combined salaries to their children, one in France and the other in Spain, totaling \$450 a month. “It’s an investment in the future, that’s why I do it,” her father told me. The family owned the four-story house where they lived, and Mr. Sylla rented out the bottom two floors for income. His accounting and fiscal management skills were strictly applied to the family as well. They barely made ends meet.

At the time of our first meeting, Rokhoya was enrolled in a trade school pursuing a degree in *enseignement technique féminin* (technical education in feminine work, loosely equivalent to home economics). She was expected to master cooking, sewing, crocheting, and “conversation” (*causerie*). Rokhoya crocheted beautiful robes out of thin yarn, without using a pattern, to fit her own form and planned to eventually produce robes to fit women of all sizes. The requirement that she master *causerie* made me pause, for Rokhoya was not a conversationalist. I initially found her a difficult informant. She seemed utterly uninterested in conversing with me, or anyone, except out of politeness when she was addressed. Even then, she would answer with the fewest possible words—perhaps a private economic exercise that she had perfected. As I engaged with her parents and siblings, all of whom wanted me to know

the twists and turns of their story, Rokhoya stared silently into the room, offering bits and pieces of information only when I persisted in engaging her. She could not bear to look strangers in the face. If her head was not lowered, her eyes darted elsewhere. I decided to leave her alone, to see where the conversation would take the rest of us and whether she would ever feel compelled to join in.

Mr. Sylla wanted to speak in English when he could, impressing his wife and children, who sat on the floor. I tried to steer him back to French or Wolof, which he used interchangeably, like many people, so that the children could participate in our conversation, rather than being intimidated by their head of household and the foreigner (*tubaab*) there to learn about Rokhoya’s disease. Mr. Sylla had an imaginative memory, going beyond lived facts with inventive details. His wife and children corrected him. “No she was hospitalized for a bone infection, not a crisis.” Rokhoya only participated at strained interludes, to correct her parents regarding the dosage and frequency of her medications. She “had taken fagara,” a traditional plant remedy widely used for sickle cell, for a few months in her early teens but did not think that it had helped. She also nodded reservedly when her parents described their meticulous home care and their optimism about her health as a consequence of it. Years later, she would tell me, through a flood of tears dammed up only by desperate gasps for breath, that her father’s care saved her life. I first heard this care described in the following exchange:

Mr. Sylla: Where we live—we live in an airy apartment. A crowded, enclosed space [*la promiscuité*] is dangerous for her. We rent out the bottom apartments, the ground floor, so that we can take these top floors. We also have an open roof [with a courtyard, kitchen, and bedrooms] so that she can breathe pure air. She has her own bed, her own room. This way she has her own air.

Mme. Sylla: And no one is allowed to light the incense stand in her presence . . .

Mr. S: Incense—smoke of any sort, really—when there is a smoker here, we intervene right away and say: “we are all, the whole family—is allergic to cigarettes, all of us [*tous*].” Even when there is a smoker out crossing the street in front of the house, the children will come and tell me, “Papa, there is someone smoking in the street.” We are allergic to cigarettes, and do not permit anyone to bring cigarettes near Rokhoya. This training [*entraînement*] is key. No one crowds her [*ken du ko xatal*]. She has everything—a practical environment to prevent her crises, to space her crises. We operate this way and pray to God that we start to tend toward actually eradicating her disease . . . We are optimistic. This is an incurable malady . . . One of her doctors told us that there is a vital relation between the disease and man.²⁶ The essential thing for us is to correctly care for her and

to promptly give her the assistance she needs. We are guided by these objectives, and we are optimistic.

As if to demonstrate their vigilant guardianship, a few minutes later, a report of a smoker came from down the hall where Mme. Sylla had gone with Rokhoya to retrieve her daughter's handiworks to show me. "There is someone smoking here!" Mme. Sylla yelled. "Is there a smoker in the building?" Mr. Sylla shouted out down the hall. No one responded. "It's not in the house, it must be outside," he continued in his normal voice. He then resumed our conversation.

It is important to constantly keep an eye on her, and to believe in God, and to strive for the best well-being possible. As they say in French, "Tout homme en bonne santé est un malade qui s'ignore" [A man in perfect health is simply an unknowing patient]. It's rare to find a human being that suffers from nothing at all. We have inculcated ourselves with this mindset [*esprit*] and we live this mindset in our family. All that she needs is support, our aid . . . She has certain talents, her handiwork, and the will to work. We've helped her choose a trade—home economics—which she is now finishing. All she needs is a supportive environment that will permit her to succeed.

I later learned that none of Rokhoya's friends knew about her condition. "They never asked, I never told," she responded, when I inquired about her discretion.

Six years later, in 2006, I visited her father's house again. Nearly the same scene unfolded. The children were taller, and this time they sat on chairs and cushions lining the walls. Mr. Sylla spoke in English, his wife in Wolof, and the children eyed me and tried to join in when they could. Rokhoya was still silent. I spent the afternoon with them and then took Rokhoya with me to an ASD meeting I needed to attend at the *Centre national de transfusion sanguine* (CTNS; National Blood Transfusion Center). In the taxi we talked more than we ever had. She was now 25, had gotten married, and had borne a child. She and her new family still lived in her father's house. "This is best" she assured me. Her husband was a close neighbor from her childhood. Their mothers had arranged the marriage, and the couple was happy to reunite after many years apart. Rokhoya's family had moved away from the neighborhood where her husband had lived and where she was born and had grown up until her father bought the four-story apartment. "He has always been family to me, even when I went years without seeing him. He knows my family, and we all live together without a problem." Our conversation then veered back to the sickle cell disease association, newly publicized on television a few days before, as we passed billboard after billboard showing a literal sickle cell poster child, a seemingly healthy newborn infant. The state was getting ready to host its first international conference on the disease, and aware-

ness messages lined the highway and were flooding the media. We were both surprised by the coverage; sickle cell had finally seemed to garner state attention. We spent four days meeting and talking, and I introduced her to dozens of sicklers who were part of my larger fieldwork project and who were also members of the ASD.

As the ASD meeting started and the agenda was read aloud, it seemed clear that Rokhoya recognized herself and the outlines of her life in the issues enumerated by the group's president, Magueye Ndiaye. She kept looking around, eyeing the members who called themselves a family of "shared blood." Magueye reiterated multiple times throughout the meeting that this family of blood was bound by sickle hemoglobin as the medium of their kinship.

The airy CNTS cafeteria, which opens onto a courtyard shaded by mango trees, where the group usually met, was under construction. After some commotion about finding a space where they could all fit, the group decided to convene in the waiting hall where patients usually lined up to have blood drawn during hours of operation. There were two large open doors and a smaller window through which air could move. The meeting lasted for over two hours. About 45 minutes into it, when an argument ensued over access badges to the international conference, which excited everyone greatly, Rokhoya started to cough violently and asked for water. She told me that she was suffocating because there was "no air." I directed her to the water cooler upstairs and pointed out the open doors and windows. She went to drink and to breathe. She then came back and stayed for the duration of the meeting without incident. I wondered about the coughing and the claim that she was suffocating. Was this an affective plea to return to the safe haven of her father's house? Was she not truly "at home" with the many others in the room who were sharing her air and who also needed "more oxygen"?

The majority of the ASD discussion consisted of a back and forth about which members would get a *carte blanche* to the upcoming international conference. I also wondered if the high emotions linked to the group's politics were what had "suffocated" her. As the meeting ended and we were able to talk, she assured me that she was fine and that she wanted to meet the group's president. I now noticed that her eyes were slightly wet, as she continued to softly cough and to pat them dry. When the small huddle around Magueye started to thin, she approached him to pay her membership fee to join the association. They were both "healthy" sicklers, Magueye joked. He got her to laugh by teasing that he was more "successful" than she was because he was older. Her sympathies with him and the others were clear. She would return again. She also convinced her father to join. Eventually most of Rokhoya's peers in ASD began to refer to Mr. Sylla as their father as well.

In the week that followed Rokhoya's first encounter with ASD, she began to tell me about her desires, her

plans, and, finally, her frustrations. Members of the association immediately took her in. After they would all travel together to the remote conference location (the ultrarich district of Les Almadies at the luxury hotel Le Méridian President), Rokhoya would spend eight-hour days with other ASD members in their information booth. It was in part because of a profound realization that she was “not alone in this disease” that she began to express her feelings more openly. Her disease had been “mild” but at what cost? The normalization of her illness was rooted within a context of precariousness, which she observed all around her. Most recently, she had suffered from survivor’s guilt as she witnessed a neighbor with less educated and capable parents die from the same disease because, in her words, “he lacked my health.” She also understood that her near-total health was rare, and she simply credited her father’s care. Nonetheless, by gauging the worst cases of the disease around her and comparing them with her own, she imagined that her livelihood was due to a very thin buffer, family care, which separated her suffering from that of others. Rokhoya suffered, even so; she lived emotionally bewildered at the thoughts of her special status, her family’s sacrifice, and the biosocial inequality that somehow cast the die in her favor. We planted ourselves in a quiet corner of the hotel, away from the conference commotion, to talk. We had never done a taped interview before without her family present, but now she was ready to tell me her story. Overlooking the city, she pointed out a mosque nearby. She then playfully attempted to find her neighborhood within the city sprawl before she settled into her chair. Her smile began to fade.

Duana Fullwiley: When I first started talking to your father about your disease it was clear that his care played a large role in your health. Can we talk a bit about that, and how you see your father’s actions? It’s important that I also understand your take on things.

Rokhoya Sylla: What you’re saying is true. Sick cell demands care, and understanding, and support. When you’re tired, you need rest, you need air, and a way to avoid getting stressed or tired about small things. And my parents, they understood me—[she begins to cry], when I was tired, they—[she stops and can no longer talk] . . . they supported me. [Through tears, her language gets confused] everything they did, nothing ever lacked [*sama dara defa mesul manqué*]. They did things for me first, then thought about the others. I came first.

I asked if she wanted to stop the interview. She gulped and shook her head no. She regained her voice and we continued.

DF: When you first realized all of this, how did you feel?

RS: When I was small, before I really understood the disease, I felt guilty. They would take better care of me than the others. I was special. Later we found out

that some of the others had sickle cell too [sickle cell trait] . . . [begins to cry again].

DF: What is it that is making you cry? What is it that is touching you to make you cry like this?

RS: I’ve just lived so much. The disease, you can’t understand . . . And when you asked me about my father—I just can’t explain [chokes up].

DF: I’m sorry [*massa waay*].

We stopped the interview. I handed her tissue after tissue until her face was dry of tears. Her eyes were locked on the city, to avoid looking at me, as if seeing me meant exposing more than she could bear. She then balled up the whole disintegrated mass of tissues in one hand and clenched it tightly. She forced a smile to say she was “fine” [*ça va*]. She began to gather herself emotionally again as we sat in silence for a while. Small reminders of the world—birds cutting into the view, a maintenance man below—allowed her to gradually speak again, if only to comment on the scene. She eventually found her way back to a not-so-lost thought and resumed the story of witnessing her neighbor’s recent death from sickle cell because his family “didn’t have the knowledge, the means, or the interest” required to keep him alive.

In our exchange, Rokhoya’s tears appeared to me to be a metonym for the well of emotion she had guarded quite carefully through years of silence. When we stopped the interview, she allowed me to sit with her, as she tapped her hand on the arm of her chair and nodded to me to both wait and to just be with her. Her tears seemed to give speech to that which was beyond language (or at least communication with a nonsickler like myself); as she told me during our interview, “You can’t understand.” Silence, for Rokhoya, expressed the nonverbal dimension of communication, in this case of illness, that nonsufferers presumably cannot know because it eludes the linguistic tools usually used to convey intimate life experience (Morris 1997:27). What Rokhoya’s stunted silence made clear to me was that although I could never be sure that I could actually understand, I felt an ethical obligation to try, even if that meant leaving exposed that undeniable gap in experience between myself, the anthropologist, and the woman trying to speak through her pain. As she seemed to want to talk and overcome the physical blockage of her gasps, it appeared that our interactions may have enabled her to see what was at stake in her health, why it so conflicted her, and, more importantly, the extent to which it was a societal issue far exceeding her as an individual (Kleinman 2006:210–212). In the days we spent together at the Méridian, Rokhoya gradually breached her silence with more ease, especially once she found the sickle cell patient group and was able to listen to her own experiences recounted in the stories of its members. In the group, she found a family of shared blood whose proclivity for, and

seminormalization of, silent suffering mirrored her own—except that their organization was now giving a voice to the void.

As for how Rokhoya felt about her biological family, the message she wanted to convey may have been interrupted by her emotions but was nonetheless clear. She loved her father and was deeply grateful for the life and health he helped her to achieve. All that he had done, she explained, probably meant that he “loved her more” than his other children. She later told me that she bore the name of Mr. Sylla’s mother. Through this assimilation, his mother was able to live on through her. In this custom of nominal incarnation, called “turaandoo” in Wolof, Rokhoya’s relationship with her father was doubly knotted: He was centered in a timeline of parental affection in which Rokhoya, diseased or not, embodied the bonds of familial past and future beyond any straightforward notion of lineage.

If Rokhoya’s disease was made “mild” by the medical care she received, it was only because that attention was complemented by an extraordinary degree of familial investment and “training” (entraînement), as her father put it. Given his limited means, as well as the number of people he had living in the household and whom he was supporting abroad, that Rokhoya had her own room speaks volumes. He not only provided all of the materials she needed to continue her schooling and pursue the trade the family had chosen for her, and that she was quite happy to follow, but he also wanted her to have “her own air to breathe,” a notion I never encountered in conversations with anyone else in Dakar. Mr. Sylla believed, like health philosopher Georges Canguilhem, that “in order to discern what is normal or pathological for the body itself, one must look beyond the body” (1991:201). In applying this idea, Mr. Sylla believed that “health is a set of securities and assurances, securities in the present, assurances for the future” (Canguilhem 1991:198). His daughter’s chances for the future, and her belief that she was important to its making, may have kept her crisis free since she was a child.

Rokhoya’s father not only implored her to live beyond the confines of her illness but he also managed to ensure that she had decent care. He always bought her the needed vitamins, painkillers, and vaccines, and he had her blood work done at the expensive, and usually reliable, Pasteur Institute in Dakar, where he had friends who would sometimes perform analyses and vaccinations at a discount. His rational philosophy of health was enabled by his ability to buy her lifelong prescriptions, and through them (largely folic acid supplements and sometimes traditional medicine), Rokhoya was able to stave off her crises and approach a degree of normalcy. This state of near health was normalized by the family’s adherence to the idea that everyone lives in a state of health defined as “life in the silence of the organs” (Canguilhem 1991:101). For them, the imagined dormant disease in all of us could begin its cry, if it

had not yet done so, at any time. Rokhoya was no different from anyone else in the human masses of the eventually sick, except that she already knew her disease and was therefore a bit more enlightened on this matter of eventual risk than most. Other HbSS sicklers constructed ideas of the normal very differently—through an impetus to build family to supplant strained or failing solidarities of birth kinship and national citizenship. This happened through dire economic lack, rather than relative economic prosperity.

Training the body for minimal need

He lost his appetite . . . He lost his “taste” for food, and now he lived on coffee.

—Nancy Scheper-Hughes, *Death without Weeping: The Violence of Everyday Life in Brazil*

Magueye and I sat under a whirling ceiling fan, which did little to break the heat in the enclosed courtyard of the new French bistro across the street from the children’s hospital. I had made it my ethical duty to fatten him without his knowing that I harbored such a strange project. Instead, I played on his penchant for hospitality and said that I had no one to eat with, as it was Ramadan, and asked him to keep me company during lunch. Because of his disease, he was not supposed to fast, but he was fasting anyway. I succeeded in talking him out of it, theoretically, with the help of a doctor, and then immediately, with the promise of pasta *avec sauce béchamel*. Practically speaking, I knew that Magueye fasted on most days anyway—not out of choice but out of circumstance. He had become rail thin, and it bothered me, not solely because my very presence next to him implicated me in the global inequalities I palpably felt after the eight-hour trip between JFK and Léopold Sédar Senghor airports but also because it was clear that on this day Magueye was working as hard as anyone in the humid heat of September in Dakar. He was on his self-appointed rounds visiting sicklers throughout the hospital sector while living on fewer calories than nutritionists think humanly possible. He was six feet tall and could not have weighed more than 130 pounds.

As we sat down, he commented on the skills of the waiters, the rules they were breaking, their inability to carry more than one plate at a time. He was an expert in restaurant management—a strange paradox, given that lack of food was the tool by which he trained his body for scarcity, constantly raising his threshold for alimentary needs. Magueye was good at making his disease seem less like an inconvenience and more and more like a way of life.

The waiter brought us a basket of sourdough rolls to hold us over until our order arrived. Magueye picked one up and smiled.

You know, I used to eat one of these for lunch every day when I was a kid. But it wasn't just for me. It was for me and my friends—those of us who couldn't go home for lunch, because we didn't have bus fare. And if we did go home it wasn't clear that there would be much to eat. So we shared this little thing [his eyes fixed on the roll he'd begun to twirl in his hand like a toy].

Magueye's account made me wonder about the sharing of food in general in Senegal. Families and guests usually eat from one plate, sometimes (traditionally) with their hands—a social fact that bespeaks the intimacy of eating with others in general. But, more specifically, whenever I offered children something, they would share it among themselves, whether they were poor or not. I often gave food to street children (*taalibe*), who would rush to me when they saw me near the busy thoroughfare on my way to the transfusion center. They too, even in their very dire situations, would divide whatever they were given among themselves, even if the biggest boys would take larger shares, leaving the little ones with stark lessons about might being right.

Magueye was the youngest of nine children. His father was a military man, a gendarme, and his mother, a Peul woman, lived (and continues to live) off her cows. After his father's death, when Magueye was just 14, he moved to Dakar from his village of Khombole to live with his older brothers, who were in the city attending school. Why did they not provide for him? I asked.

I don't know. I think I was too young to question it. That's how it was. My brother gave me 200 CFA a day [40 cents]. I had to take two buses to school, which means a transfer and paying again, so I had to content myself with the little change I had left to get something to eat. My friends and I, we would go in on the roll together. We couldn't go home if we wanted to. There was no way around it.

Magueye presents this situation as normal, and for many poor sicklers in Dakar who recounted "not being able to go home for lunch," the assumption, indeed, was that they would fend for themselves, or, more likely, wait for evening when they might eat at home.

Later he related this training in surviving scarcity to the fact that he lives well with, not despite, his sickle cell disease.

Magueye Ndiaye: I have learned to manage my crises largely without all of those pharmaceuticals. It's awful to be dependent on something—it's a hard thing to feel dependent on medications. It's especially difficult for me because I don't even have access to pharmaceuticals. I don't have the means to buy the meds. Sometimes I have a prescription that sits [*qui dort*] for six months. I don't have a cent to buy them with. Given all of this—the lack of means, access, the hospital costs—

I say to myself, listen, since I can't access medications, I don't have the necessary means to always be buying myself medications—while I know that I need them incessantly, always!—then why not use another therapy? What I call psychology. It's mental. It permits me to get by.

DF: The access you're referring to, is it principally an economic problem?

MN: For me it's entirely economic. The meds are at the pharmacy. [There's no disruption in the supply these days.] But I can't . . .

DF: Which medications? Folic acid tablets?

MN: Folic acid is what we need at a minimum and, you know, the price is around 2,000 CFA [\$4] a month. I can go a whole month without having 2,000 francs, a whole month without 2,000 francs. Imagine! And, I have other things to take care of, too. I have my breakfast to contend with. I have tons of things that will come first.

I inquired about how he coped with his dire economic situation.

DF: How do you live? [silence] . . . on a daily basis? You are unemployed. How do you do it?

MN: I also ask myself how I do it. How?

DF: You don't have a daily allowance, a DQ [*dépense quotidienne*]?²⁷

MN: I don't have a DQ. And I can't ask anyone for anything, but things come, just like that. It's weird.

DF: In the morning, for example . . . recount your day for me.

MN: This morning, for example, I knew that I had my round-trip bus fare taken care of by the health ministry [since he was helping them organize the upcoming sickle cell conference]. And other than that, I had 5 cents [25 CFA] in my pocket, or something like that. So, I buy a little baggie of coffee along the side of the road, the 5-cent sachet, and I drink it calmly and slowly. It's my breakfast. Sometimes I don't have . . .

DF: Only a 5-cent cup of coffee?

MN: Yeah. Sometimes I don't even have that. I drink a glass of water, and then I'm on my way. And you know, in this way, I have learned—naturally, I have no appetite. It's innate with me. Everyone knows—eating [*le manger*], or not eating, has never held me up. This, in any case, permits me to self-manage better [*de mieux m'auto-gérer*]. I tell myself that there is not a set hour for lunch. Just because it's twelve noon, doesn't necessarily mean that it's time to eat. No—that has never been part of my schedule.

DF: I see.

MN: Sometimes from sunup 'til sundown I simply drink water. But I'm well in these conditions. That's it. As soon as it is evident that I cannot have what I *want*, I content myself with what I *have*. If I have a glass of water, I drink it and I'm on my way. If I have a cup of coffee, I drink it and I'm on my way. If I have nothing—I'm on my way.

Magueye's case recalls Veena Das and Ranendra Das's observation with regard to chronic sufferers in urban India that, "within both the medical system and within the distribution of power and resources within the household (or economy) there operates a patterned non-recognition of severe disease that helps to absorb serious pathology within the normal" (2006:194). In part, it is this patterning that renders his disease mild. Yet Magueye was not always able to manage his disease with ease. He also told me of times when he was in dire need and local specialists, all of whom knew him well, would let him "borrow" money—which, it was understood, did not necessarily have a repayment date—to stock up on folic acid. The main specialist at the children's hospital, who was also from Khombole, opened his wallet when he once saw Magueye tear up a prescription he could not afford; he also bought Magueye shoes and other necessities on a trip to France soon afterward. Magueye's personal doctor at the CNTS would periodically "get hit up for bus fare, a few francs here and there," when Magueye was in need. "It is no longer like doctor and patient," Magueye told me, and that is when he said, "It's more like big brother–little brother. He looks after me."

Magueye, like other sicklers I knew, initially diagnosed himself after learning about the signs and symptoms of the disease in a natural science course in middle school. He was 14. His teacher recommended that he see a doctor, who made the diagnosis official. When I asked if his parents had detected anything wrong during his childhood, he said that his mother first noticed a strange swelling of his hands and feet when he was only a few weeks old. They were on a long road trip in the Casamance region, where his father had been stationed. "It was hot," Magueye imagined, and "I was dehydrated." His mother said that he did not stop crying for nine hours once the "hand–foot syndrome" set in. His parents were confused about his recurring symptoms and took him to traditional healers for years. Some of the healers cut his small body with razors and inserted herbal mixtures into the thin slits. Others gave him tonics and infusions of various plants. Still others wrote Koranic verses on pieces of paper, neatly folded them into squares, and enclosed them in leather casings, which he was to string around his body for protection. In this medley, which he described as a "barrage of therapies of *hazard* [Fr. chance]," he was sure that fagara, an element of Senegal's pharmacopoeia that Rokhoya also took as a child, was included in the mix. Sicklers, Catholic nuns at mission health posts, healers called "traditional," and even biomedical disease specialists all distribute this

botanical, known as *dengidëk* in Wolof. Magueye recalled a plant that sent vapors to his nose, "like mint," and that had a particular smell and taste. As an adult, he learned that the remedy he took as a child was fagara when a friend with the disease began buying him small sachets from the market when he was not well. "I could never forget that smell," he said as he breathed in, holding his body.

Provisional foresight: Imagining future family lines

When we think of the world's future, we always mean the destination it will reach if it keeps going in the direction we can see it going in now; it does not occur to us that its path is not a straight line, but a curve, constantly changing direction.

—Ludwig Wittgenstein, *Culture and Value*

Magueye received his high school diploma, which, in the French system, demands a rigorous test (*concours*), after the second try in 2000. He was 24 years old. He enrolled in university, negotiating to do one semester a year, but even that proved too much for him. He soon dropped out and decided to pursue English classes at the American Cultural Center in Dakar the following year, but he fell sick. He decided to change course again and opted to go to cooking school. He had never had an appetite, but the high culture of French culinary practice intrigued him. He finished his training and had job offers soon afterward. He was proud of himself for finishing the course, and for having a trade, but also had to admit to himself that the heat of the kitchen, the stress of the line, and the long hours on his feet were not compatible with his illness. He now caters private parties on occasion, about five times a year in good years, and still hopes to build a client base. His catering "contracts" usually stipulate that he work long hours, often until early in the morning following an event, and they pay no more than \$10 for the night. He always welcomed these opportunities, however stressful the labor.

Magueye spent his days, for the most part, at the adult sickle cell clinic and in the teaching hospital environs, where he would look for sicklers who might be in need of support. He gave them everything he had. As if proposing a plan that I might help him realize, he often talked about imagining ways to change the nature of suffering, to be able to transfer actual physical pain between sicklers who were "overloaded with crisis." Sometimes over coffee, he would imagine a kind of "transfusion" technology that, like a blood transfusion, would export suffering from a sickler to another person who could better tolerate it. He imagined that God would have to "update human capacities," and biological nature, to make this possible. He thoroughly enjoyed these musings and would laugh at himself for

wanting things to be otherwise. In 2004, when he was 28, he was voted president of the newly formed ASD. This voluntary work made him feel useful on several levels:

Every morning I go the CNTS. I don't actually work there, but it's like a second home. I feel at home there because that's where the sicklers are and at least over there I feel I'm serving a purpose. I counsel them, I orient them, I share pain with them. Sometimes they ask me to come to their homes, or parents will ask that I come and see their kids because they refuse to take their medications. Sometimes they ask me to come and talk to their families about how to live well with sickle cell, how to manage it. Many people ask me, in disbelief, if I'm even an [Hb]SS sickler. Why? Because I have learned to live with it. It doesn't throw me off. I'm at peace with it. And I love these people. I am always thinking of them. I'm always thinking of how to advance things here in Senegal for their benefit, how to help them live with the pain. It's good, because it busies me. When I'm unemployed and I'm just sitting around idle, that is a much more difficult situation to be in. It's better to feel useful, especially for a cause.

In fact, the ASD served a double purpose for Magueye. For many of the people with sickle cell I encountered in Dakar, creating a *heritage*, a family line, was a special kind of investment they deeply believed in, but it stymied them in practice. For Magueye, this notion of legacy was strong, but he constantly questioned his desire for it because the woman in his life, Safietou,²⁸ was also an HbSS sickler. Magueye was not yet sure what to do about his dilemma, because, genetically, there was no room for doubt: He and Safietou could only have HbSS children. In their case, with the calculations of risk settled, the matter at hand was whether or not to continue their relationship, to live it only in private (a near impossibility given familial pressures to marry), or, perhaps, to think about other forms of heritage.

MN: If people don't want [Hb]SS sicklers to marry each other, it's because they are thinking of their children, about the family that you will found. But what if we aren't necessarily thinking about that?

DF: So you do not want children?

MN: I'm just saying that, for the moment, we don't have the future figured out—marriage or children. We simply want to be able to support each other, mutually. Each of us knows, on the inside, that we are both sick. But, we understand each other—between us, . . . we've established a climate where we don't consider ourselves sick sicklers. We live, we go out to clubs. We go to the beach, like "normals." What is the problem? The essential thing is to be happy.

DF: And if you want children, eventually? Can you stay together and forgo having children? Would that be too

weird? We see lots of childless couples in the U.S., for instance.

MN: No. In our society, that is not recommended.

DF: Why not, if the child would be sick?

MN: You know, I'm going on what I am. In the Muslim faith it is said that you must marry and have children to augment the race, you know?

DF: The race?

MN: The race—to augment the number of Muslims in future generations. When one is born into a Muslim family, you are Muslim, and you continue reproducing Muslims. That's how it is. We are here to increase the number of Muslims.

DF: The Muslim race, is that it?

MN: No, not the Muslim race, but the black race, you know. There is not, technically speaking, a Muslim race [laughs].

DF: "The black" race? Doesn't Islam first come from Arab culture?

MN: Well, to augment the genealogical tree—well the tree is there, I'm here, but no one has the right to simply stop the tree with himself. Like, if I refuse to have kids . . . the line stops with me, the line becomes extinct, and that is a problem.

Magueye's quip about "race" is more precisely about lineage. Many Senegalese recounted that, to be a good Muslim, one must have children. This was stated less as a pressure than as an opportunity to please God and to partake in the larger outlines of conduct he proposed to humanity. Senegalese Christians had similar views. Magueye continued,

When I talk to my friends about marriage, I get into discussions about the point of marriage. What is it for, at the end of the day? And they say that it—well, they don't exactly say that it is for having children, but they say that it is a way to preserve—if you die one day, to see you through the person you have left behind. Then I say, "instead of creating a person, I can create a thing, through which you will be able to see me." I can forgo marrying, do without having children, and instead fight for a purpose and build so that Senegal has a specialized center for sickle cell where the fight to better sickle cell care will live on. And everyone will say, "Magueye Ndiaye, he was part of this." That, too, is a heritage. It's like a son one leaves behind after death, who will continue to serve the world. So don't tell me that it is imperative to have an actual son or daughter. Sometimes I defend myself with this rationale . . . Sickle cell is my heritage, and I depend on it [*j'y tiens*]!

Magueye nevertheless did want to marry and have children. He constantly discussed it with an older, motherly friend whose HbSS child had died recently. They both got animated, and sometimes argued furiously, when she told him not to get too involved with the woman he loved. The friend, Mrs. Touty Niang, was also part of the governing body of ASD. As Magueye and I continued our initial conversation about marriage, I attempted to think with him about his future possibilities and heritage, given his relationship. He admitted a future with Safietou might not be possible, given the pressures from his biological and other relations on two completely linked fronts: marrying someone with the disease and not being able to have (healthy) children.

MN: I can tell you that right now everyone is talking to me about marriage these days. Everyone brings it up, I don't understand why.

DF: Do you think that it would be possible for you and Safietou to marry, [Hb]SS and all, and that the two of you could have the association as your heritage?

MN: If it was just the two of us, we could do it. The problem is that each of us is issued from a family, and everyone knows that we Senegalese have a very, very heavy social context to deal with. I can decide as an individual to make such a decision, she could too, but they will never let us live in peace, as we would like. Maybe it could work if we left the country. In order to live your life in peace, without considering the family—it's not possible, unless you are disowned. If you do something like this, you will be banished. No one in the family will speak to you again.

DF: Because of not having children?

MN: No, because you're living your life the way that you see fit, disregarding their familial expectations. It's difficult. Me, I don't want to commit to a decision like that.

DF: So, what would be the basis of the exclusion? Is it the fact that you've married another [Hb]SS sickler, or the fact that you've decided, in doing it, that you don't want to have children? . . . What kind of exclusion do you imagine?

MN: I think—I tell myself that the exclusion will essentially be because you've decided not to have children, and that you've decided to marry an [Hb]SS, while everyone knows that that just isn't done [*que c'est pas normal*]. So, these are decisions that you can make, when you love each other, but there is the family that imposes itself, and the family can then decide to never speak to you again, and you'd live with your wife in solitude. That would be awful. At the very least, we need our families.

DF: So you really do think that your family will reject you?

MN: Yeah, you know there are families . . .

DF: Yours?

MN: Yes, mine. There are certain things that are not pardonable, frankly. I'm sort of spoiled because I'm the youngest and all, but there are issues that they just will not tolerate. Even the association [ASD] would not forgive me for that.

DF: Your other family . . .

MN: [laughs] Yes, my second family. Even my doctors would say, that Magueye, he did it on purpose, so just leave him to live alone with his malady. In any case, I do know that there is a pretty strong possibility that *I will* marry another sickler. Frankly, it could happen. I'm not *deciding* on this. It's not my wish, but I'm not fleeing the possibility either. I'm not *seeking* it, but also, I'm not against it . . . Medicine has its limits, you know. Science—has its limits! . . . I am really tempted to do it, you know, maybe to prove that we could have healthy children. Sometimes I even wonder if I really have sickle cell. I've taken the test many times over, but sometimes I really don't believe it.

Senegalese family pressures to reproduce, the physician's lectures against knowingly bearing children who might have the disease, and even the general message of the ASD, in its fight "against" sickle cell, have laid out certain norms of conduct that collided with Magueye's hope to pursue his relationship with Safietou. For a time, he continued it anyway, refusing to "make a decision" while rattling off a few rounds, back and forth, about how he was not actively for or against such unions. At the end of the above conversation about being with an HbSS sickler, Magueye brandished his own health as a means to question the interdictions and the prognostic capacity of science to determine whether or not his own child would be sick. There was a part of the scientific narrative that he knew to be true. He felt, however, that it had limits, given his level of health and individualized norms he had achieved through methods on which science may have little comment. For Magueye, having children at all costs was also an expectation framed within Islamic theologies. Augmenting his family line was, moreover, framed as increasing the Muslim population of God's children. In our conversation, his idea that he and Safietou should just marry and experiment with having children, to "prove" that they could be healthy, despite the technical impossibility, drives home the extent to which his own norms had come to trump those of science on this question.

Magueye Ndiaye's biological norms however, were anything but fixed. After the 2006 international conference, his stress from being the public face of ASD, his unpaid work at the CNTS, and his side attempts to make money to save for marriage brought on two painful crises, one of which landed him in the hospital in the winter of 2007. Safietou spent most of her days and evenings with him, which made it obvious to Dr. Diagne and others that the two were

romantically involved. Diagne was visibly frustrated and worried that Magueye seemed to be flouting the message of ASD on prevention. He nonetheless said that Magueye was “his own man and would have to make his own decision.” A few years later, Magueye told me that Diagne, whom he called his “spiritual father,” in the context of this conversation, had made it very clear to him that if he married Safietou, he would have to resign as president of ASD. Diagne had no power to fire him, but Magueye understood that he would suffer a crisis of legitimacy if, as ASD’s president, he openly married a woman with sickle cell. Magueye also referred to Touty as his “spiritual mother” in his account of how she also asked him to “think of the consequences.” The decision to end his relationship with Safietou was a moral dilemma that made Magueye realize that the network he had helped to create that permitted those with the disease to share pain was also subjectively inseparable from him. He could not imagine life without it and began to realize how much he relied on the very supports he helped bring into being for others. There was no question of sacrificing his work with ASD to pursue a love that was about his own wants. To do so would have been more “selfish” [*égoïste*], he said, than social. In this way, he made the decision to leave Safietou because of their shared sickle cell blood.

During the following years, in 2008 and 2009, Magueye tried to reconcile his feelings and kept himself busy with several projects to better the plight of sicklers in Senegal. In addition to working on a vaccination campaign funded by the telecommunications company’s charity organization, *Fondation Sonatel*, he drafted two interrelated projects of his own. The first was a plan to start what he described as a “nonprofit health insurance–microcredit agency for sicklers” [*une mutuelle d’épargne et de micro crédit qui servira comme une mutuelle de santé en plus*]. In his conception, people with the disease would be the shareholders, pay a set monthly premium, and be able to borrow larger sums for projects, for hospitalizations, and for pharmaceuticals when necessary. This hybrid of economic and health support would, according to his business plan, “come to the aid of economically vulnerable patients and further develop a cadre of solidarity within ASD,” out of which the *mutuelle* would be run. Magueye hoped to find investors who would front the initial capital, and he also hoped that some of the many projects that ASD’s unemployed members had imagined for their economic futures might come to fruition, such as the boutique Rokhoya wanted to open upon finishing her latest set of courses in 2010. Magueye had already succeeded in enlisting a pharmacist who is an HbAS sickler (i.e., who carries the trait) and who felt a personal interest in sickle cell entraidé to provide medications at a discounted rate for those within ASD who might join the *mutuelle*, the nonprofit microcredit–health insurance plan.

Magueye’s second project was a quasi-ethnographic study of sickle cell and relationships. He sought my help

to formulate research questions on intimacy and sexuality based on major themes that he and others had lived. “There are so many people suffering from fears that they will never find anyone, and there are others who wonder about how the disease affects sexuality, with symptoms like priapism,” he told me.²⁹ “I can’t count how many women don’t think that they will ever be loved because they have this disease. They feel lesser [*wañeeku*]. They need to know that they are not alone in this.” Magueye’s very position as president of ASD made him a natural confidant for both men and women, and he wanted to somehow catalogue all that he was hearing into some kind of formal study with “data.”

During these years, it became clear that the moral dilemma that Magueye faced with Safietou was partially structural; he felt a deep connection, a closeness, a sense of family with sicklers. He often said that he “loved them,” adding, “I even love the ones with horrible character flaws, who I’d *love to hate*! It’s impossible.” Thus, not surprisingly, he later became intimate with another healthy HbSS woman, whom he dated quite seriously in secret, fearing reprisals from her family and from ASD’s biomedical supporters. After a year, however, “a university trained, polite fellow from a good family,” according to Touty, asked for the woman’s hand in marriage. She refused. Her family could not understand why she “chose to remain alone.”

Magueye then took it on himself to pull himself out of what was becoming a painful pattern and resolved to marry a non-HbSS woman, “as a safeguard,” he said, to keep him from becoming too close with women with the disease. “We have no future, it’s useless,” he told me, and himself. Almost as a seeming reflex, Magueye went to his birth kin for a suitable wife. This is not uncommon in Senegal, but what is interesting about Magueye’s choice at this juncture in his provisional efforts to eke out his future is that, for much of his life, his birth family could not provide for him so he created bonds of sharing and solidarity with others, from the kids with whom he had shared bread for lunch to the sicklers who offered him a heritage. Now, when two love relationships with women, who were not of his same Peul ethnic group and who were not birth blood kin, threatened to compromise his family relation to the ASD, he almost naturally went to his other “bloodline” and decided to marry a Peul cousin from his natal village. “I was home for the Tabaski holiday and I saw her around, and meant to talk with her, but lost track of her that night. I asked my mother about her, and my mother said, ‘That one? She will be your wife.’” He talked to his cousin indirectly about marriage over the next few months. While they dated, she let him know that “he wasn’t the only one with an illness.” She was not talking about sickle cell, however, as she had not been tested at the time, but, rather, gave him a laundry list of all of her “ailments,” from chronic allergies to frequent colds to snoring, to convey to him that she was capable of understanding the chronicity of sickle cell. He said that

he laughed at first but realized that she was serious. She wanted him to know, perhaps like Mr. Sylla, that what made anyone normal was that “we all suffer from something,” as she later told me.

Magueye had his cousin tested for sickle cell at the CNTS in the fall of 2009. He worried because, as he said, “everyone knows that consanguineous marriages pose the same risk as marrying someone in ASD,” his other family. Even though people from the Peul ethnic group are sometimes seen to be more at risk for sickle cell because of popular understandings that Peul rates of first-cousin marriage surpass those of other groups, Magueye’s wife-to-be did not have the disease or the trait. He came to believe that her genetic lot was more than luck (Fr. *chance*); he began to see marriage to her as both his biological destiny and opportunity. Soon afterward, Magueye announced the wedding to his ASD confidants, specifically, to one of his former loves. Out of what I took to be one of the most selfless forms of care for him, she took the lead in planning the ceremony within ASD.

Magueye, a self-pronounced “healthy sickler,” created various relations, enacting kin ties on multiple registers. He ended up marrying a cousin from his Peul ethnic group, who did not have sickle cell but who nonetheless shared his “other” blood at the level of the family, as she was the favored wife that his mother had likely chosen for him, a choice that he may have secretly resisted for a time. In forgoing his “selfish” love relationships based on shared understanding and suffering with other HbSS sicklers, Magueye was nonetheless able to maintain the biosocial future of ASD, his heritage with a larger community of sicklers who shared his diseased blood. This happened in a biosocial nexus that medical anthropologists have called a “kinship of affliction” (Heath et al. 2004:204; Rapp 1999:277), which, for Magueye, was always and equally a kinship of affection.

In Senegal, as elsewhere, biological kinship remains an impressive force that continues to shape people’s options for the future. The thought of his family’s reprisals if he should brazenly marry a sickler, that is, enact a clear social and biological reproduction of his own condition, muted Magueye’s initial hopefulness that he and Safietou might one day have had a “normal” child with HbSS disease. In fact, he knows it is “not normal” to even consider it. He and his cousin are now expecting a child, who will not have his disease. In conversations with other sicklers I met in Senegal, the domain of marriage is where the level of health and the new norms sicklers acquire, through what many describe as therapeutic support networks, collide with the limits imposed by the genetic rules and societal taboos related to passing on their disorder. Magueye could not “just up and marry whomever [he] wants.” Instead, he created other options for eventually bettering the plight of people with the disease. These ranged from bringing intimacy into public discourse on sicklers’ well-being as a human need

that they should claim for themselves to trying to create a formal mechanism that would allow people to economically share and support life projects, as well as acute economic or health crises, through literal and figurative micro-credits of accumulation and exchange of shared sentiments within *mutuelles* of health.

Conclusion

The people whose health outcomes Magueye Ndiaye hopes to affect are those described by scientists as living a “mild” disease because of specific patterns in the genetic sequence where the sickle cell gene is located. What might genetic science gain by considering social relations of care and the intersubjective ethical concerns of people like Magueye who strive to extract the other’s pain through biosocial affinity? What can geneticists learn from families like the Syllas, who normalize disease propensities and who make household cash flows center on investments that establish genetic health rather than disorder?

Senegalese people with sickle cell anemia in Dakar live their disease via concrete particularities that extend beyond the individual. Through their illness, they form social bonds that are woven interpersonally through a fundamental sharing of pain and hope, through collective action and civic caretaking of an illness that has not been inscribed within global health priorities for Africa. In Senegal, sicklers’ mutual investment in, and ownership of, the blood they share creates an ethics of governmentality that moves analysis beyond descriptions of “biological citizenship” (Petryna 2002). Not every contemporary nation-state allows people citizenship rights through biological suffering. As Adriana Petryna (2002) has shown in the case of post-Soviet Ukraine, biological citizenship forces people to construct profitable vulnerability to claim compromised health care, and they are successful in doing so within the confines of the formal state system. In Senegal, by contrast, the state has not committed to any configuration of health care benefits that its citizens with sickle cell might reap. In the absence of even compromised social securities, people with the disease create their own care structures and economies of shared aspirations for health, and in so doing they often render their disease mild. By bringing the powers of sicklers’ therapeutic economies to bear on genetic causation, I hope to expand scholars’ visions of informal economies in Africa. In Dakar, people’s mild sickle cell expressions and normalizations of illness emerge “below the state,” and their success in providing fellow citizens with health structures of support actually aids national governance by remedying some aspects of state failure. Still, sicklers within ASD hope that their vocal politics, and their potential kinship ties with the Senegalese first lady, will eventually make inroads at the official level. Clearly, ASD’s ethical commitment to improving sickle cell well-being, for which Magueye Ndiaye lives and which

also constitutes his “progeny,” has its causes as well as its effects.

The Senegalese state’s inattention to sickle cell, sometimes called “neglect” by my informants, has “causally” spawned an intimate species of biopolitics. Here, caring as a form of sharing affliction lies with individuals who are linked through biosocial bonds that motivate them to make their health, and its norms, fit with the cultural, familial, and economic resources they have available. In recalling the government’s triaging of health problems and informal economies that shape valuations of Senegalese “mild” sickle cell, one must also ask, what effect does “biological difference” have in this contemporary global setting? Different sorts of biosocial configurations emerge in places heavily marked by dispossession. In many parts of Africa, people mobilize biosocially to address layers of “lack” (medical, technological, and economic). “Populations” may not identify themselves as collectives, but they are grouped by surveillance programs for HIV/AIDS, tuberculosis, and maternal–child health and by postcolonial demographic normalizations of the locales where they live. When people engage aspects of these programs, and form biosocial groups to address them, they rarely align themselves around biology alone. They also respond to the specter of biology—the myriad scientific assumptions about bodies, disease, and population differences, in this case, about the genetic “mildness” of sickle cell, an otherwise debilitating disorder, in a context of economic scarcity.³⁰

Enacting mild disease as a form of medical “making do” is not an enviable feat to have to achieve no matter what one’s cultural resources may be. The reality, however, is that frameworks of relations have yielded informal therapeutic economies in which the materiality of kinship is distributed not only in shared biologies (the “shared blood” of sicklers) but also in the networks of exchange that these biologies condition. These networks provide people with supports, family ties, and a sense of normalcy that together mitigate sickle cell suffering for many. In Dakar, mitigating suffering is as biosocial as it is medical. By this, I mean that it is also a health “outcome,” which, when taken as such, has deceptively appeared to be singly genetic ever since researchers isolated haplotypes in the chromosomal region of the sickle cell gene in people from the Dakar region of West Africa. Characterizations of genetic difference are never bereft of kinships with lived global–local biologies and economies. My hope has been to enliven the social world of DNA sequence markers and to make them live socially and in solidarity with people’s cultural processes of care and biosocial ethics of survival.

Notes

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1. Present-day projects that provide data as well as references to many smaller ventures include the International HapMap Project (n.d.) and the IBM–National Geographic collaborative effort to map the origins of the peoples of the world (National Geographic 1996–2010).

2. Accordingly, they wrote,

Of anthropological interest is that these haplotypes could provide an objective tool capable of defining the places of origin of Blacks dispersed through the Americas by the slave trade. This approach will allow the calculation of the composition by African origin of many Caribbean and other New World Black communities, as long as they exhibit an appreciable HbS [sickle hemoglobin] gene frequency. [Pagnier et al. 1984:1773]

3. The phrase *sickle cell crisis* refers to a painful episode in which the red blood cells deform, become rigid, and create blockages in the vascular system. People with sickle cell disease possess a genetic variant that codes for a protein change at the molecular level of their hemoglobin, causing them to produce hemoglobin S. Hemoglobin S has a low affinity for oxygen. This is the principal cause of sickling.

4. Hereafter, I use the term *sickler*, a translation of the French *drépanocytaire*, which many people in Senegal use to identify themselves. To refer to oneself as a *drépanocytaire* was rarely seen as describing one’s full identity; it was simply one term among several, which could include ethnic grouping, gender, profession, and age, among others. In other words, *sickler* in this context should not be read as a deterministic label that unjustly defines a person and limits his or her being and becoming to illness.

5. My use of the term *enactment* differs from Mol’s, as she writes, “It is possible to say that in practices objects are enacted. This suggests that activities take place—but leaves the actors vague” (2002:32–33). I argue that visible, not “vague,” actors, including patients, members of families, and in some cases healers and doctors, enact mild sickle cell anemia in their relations to affected individuals, and do so together.

6. The root of the Wolof verb *góor góorlu* is the substantive *man*, which is then repeated for emphasis and conveys personalized action with the reflexive suffix *lu*. Slightly onomatopoeic in tone, it carries the gendered connotation that men must scramble, through gumption and pragmatism, to get things done despite the odds. It forms part of an informal phrase (*mangi góor góorlu*) that nonetheless playfully parlays a light air that allows people some degree of alleviation from the pressures weighing on them. Today, both men and women use this phrase to capture their attempts to create palliatives in many areas of life in which economic hardship requires constant “management.”

7. For similar ethnographic chronicles of how everyday Africans are strategizing survival and economic viability in the face of economic crisis and uncertainty, see Makhulu et al. (in press).

8. Interview with Dr. Ibrahima Diagne, the Ministry of Health–appointed head of Senegal's national sickle cell program, October 2, 2006.

9. This disease advocacy group originally went by the name *Réseau francophone de lutte contre la drépanocytose*, or RFLD. It was very much committed to French-language sickle cell awareness, because its founder and president, Mme. Edwige Ebakisse Badasso, felt that most sickle cell consciousness-raising took place in the English language. In an effort to gain global appeal, she changed RFLD's name in 2005.

10. Interview with Mamadou Seck, March 16, 2010.

11. Personal communication with Dr. Ibrahima Diagne, March 15, 2010.

12. Interview with Abdou Fall, March 17, 2010.

13. Mme. Wade's principal mission was to make sickle cell a public health priority so "that sicklers might benefit in terms of care and aid from the UN." Beginning in 2006, she publicly announced that the Senegalese state could not afford to subsidize sickle cell care, claiming that "the cost is enormous, especially considering that 10 percent of the population is affected." See Association Education Santé n.d.

14. Investigative journalism by Abdou Latif Coulibaly (2009), as well as radio programs, news conferences, and op-eds by critical political commentators such as Souleymane Jules Diop, describe in stark terms the state's exorbitant spending. Luxury items, such as new cars for deputy ministers, and a new, unnecessary tunnel and other embellishments along the Corniche Ouest freeway for the 11th summit of the Organization of the Islamic Conference (OIC) in 2008 were partially paid for with public funds, as roads in the hinterlands, where poor conditions lead to scores of preventable road deaths each year, went neglected. Also neglected were Dakar's 1959 drainage and sewer systems. Such irresponsibility in overseeing public works contributed to consecutive years of flooding, which displaced thousands of families, jeopardized water supplies, and, of course, led to an increase in infectious diseases such as malaria. The Senegalese paper *L'Observateur* reported that the NGO AID Transparency, Senegal also found that millions of dollars in aid money went unaccounted for in 2007, the year that much of the public construction on the Corniche took place (see Diop 2007).

15. This perception is changing, however. Whereas the second Bush administration sought Senegal out as a partner in the "war on terror" and lauded Abdoulaye Wade's openness to neoliberal ideas, the Obama administration has been less adulatory and has begun to confirm everyday people's perception of their state as lacking in transparency. On May 27, 2010, Marcia Bernicat, the current U.S. ambassador to Senegal, penned an open letter from the U.S. State Department to the Senegalese government about the implementation of a \$540 million Millennium Challenge Grant to Senegal, which will largely address issues of improving agriculture, building roads, and combating poverty and disease. Published in multiple Senegalese newspapers and discussed widely in the press, Bernicat's (2010) letter coyly played on Senegal's potential to maintain its image as a beacon for Africa while persevering on corruption throughout (corruption dominates six of the letter's seven paragraphs). The ambassador's comments provoked a heated exchange between her and President Abdoulaye Wade shortly thereafter, which was televised. Wade, visibly furious, refuted the State Department's claims and asked Bernicat for specific examples of corruption. He then instructed her to let those in Washington know about his anger. Bernicat diplomatically waffled, although USAID (2007) has produced a 107-page document on specific issues of corruption in multiple sectors. Instead, she let Wade respond with, "If you want, take the MCA [the grant] and go to a country where they

will accept these criticisms and insults." He drove home this point the following day in the state newspaper, which ran the headline, "We prefer our dignity to the billions [in CFA francs] offered by the MCA" (Diop 2010).

16. Yayi Bayam Diouf is the founder of a women's collective that tries to create resources and opportunities for young people and their families to dissuade them from illegally attempting to reach Europe. She lost her only son, 26-year-old Alioune Mar, in the summer of 2006 when he boarded an overcrowded fishing boat and headed to the Spanish Canary Islands with 81 others. One press account of her story captures her pain and her political action. "The death of my son moved me to act" [*m'a beaucoup motivée*], she says. "Instead of simply crying, I said to myself that we must fight against this deadly immigration. It was then that I created the Collectif des femmes pour la lutte contre l'immigration clandestine" (Bangré 2006).

17. One BBC account of Yayi Bayam Diouf's collective against illegal immigration makes this point clearly in its byline: "Yayi Bayam Diouf says that for the past two months, she has managed to prevent any boats leaving her home area in Senegal, loaded with migrants trying to reach Spain's Canary Islands—making her campaign more effective than all the warships and planes sent to the Atlantic Ocean by the European Union" (Sy 2006).

18. In *The Body Multiple*, Mol argues that patients' experiences of disease and professionals' medical conceptions of pathology "exclude one another" and "are done differently" (2002:35–36). I argue, with respect to mild sickle cell anemia, that patient and professional practices may be done differently, but they surely do not exclude each other. Quite the contrary. French scientists' conceptions of genetic difference, patients' ethic of living well with their shared blood, and biomedical professionals' needs to make do with economic health constraints all come together to enact this form of the disease. Mol would call this an incident in which the scientific object, clinical object, and lived experience of the object "happen to coincide" (2002:46).

19. One area in which the state influences care is through health insurance for state employees.

20. In Roitman's informants' lives, "tax" and "price" come to mean similar things when fungible goods yield margins of value for those who know how to manipulate them.

21. The CFA franc was created on December 26, 1945, when France ratified the Bretton Woods agreement and made its first declaration of parity to the IMF. At that time, CFA stood for *Colonies françaises d'Afrique* (French Colonies of Africa). In 1958, the referent changed to *Communauté française d'Afrique* (French Community of Africa). Today, CFA refers to the *Communauté financière d'Afrique* (African Financial Community) and, for countries belonging to the Bank of the Central African States area, *Coopération financière en Afrique centrale* (Financial Cooperation in Central Africa).

22. Interview with Dr. Ibrahima Diagne, the Senegalese Ministry of Health–appointed head of the national sickle cell program, October 2, 2006.

23. Interview with Dr. Ibrahima Diagne, May 10, 2008.

24. I am all too aware that the notion of "crisis" is an increasingly common analytic for Africa. I interrogate it here by presenting the various ways that people act in the face of economic scarcity to produce different forms of value, in this case, care for the self and others, even as hardships persist.

25. This is a pseudonym.

26. Here he is referring to the protection against malaria that sickle cell confers.

27. This term refers to spending money often allocated by a head of household or a relative.

28. This is a pseudonym.
29. Priapism is a painful erection due to sickling that causes vascular obstruction of red blood cells in the penis.
30. I would like to thank Kristin Peterson for helping me make this finer point on biosociality in Africa.

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