What cannot be borne alone:
An anthropology of sickle cell suffering

Severine Gendron Martel

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School of Sociological and Anthropological Studies
Faculty of Social Sciences
University of Ottawa

CONTENTS

Abstract

This thesis is an anthropology of suffering conducted with a sickle cell community anchored in Montreal, and extending to the Ottawa region. It explores the entanglements of sickle cell disease with non-biomedical dimensions of people's lives: blackness and antiblackness, the cultural stigmatization of sickle cell in Afro-diasporic communities, and evangelical Christianity, a predominant religious affiliation in the sickle cell community. The suffering shared in the sickle cell community is inextricable from their Black identities, as well as the persistence of antiblack racism. In addition, their suffering is shaped by community participants' shared histories of migration, and the presence of sickle cell stigma in their home and diasporic communities. Finally, sickle cell suffering is tightly bound up with the evangelical religious experience. While evangelical churches may reproduce and intensify sickle cell stigma, God offers dual salvation to the faithful: salvation from, and salvation through, suffering. God's promises to save from, and to teach through, suffering allow people of the sickle cell community to hope for an end to suffering, but also to find purpose in suffering. The sickle cell community thus emerges at the confluence of, on the one hand, faith; and on the other, multiple axes of social exclusion criss-crossing its participants' lives. The latter live their illness as a form of social abandonment, but in sharing their similar experiences of suffering within the sickle cell community, they forge ties of intimacy, care for one another, and collectively lift their suffering. Ultimately, it is faith that sustains the community, for it impels believers to labour toward alleviating their peers' suffering. The sickle cell community lives on, in this manner, through the sharing and the mutual gifting of its participants' suffering. As such, this thesis sutures two appearingly dissonant modalities of suffering, namely social and redemptive suffering.

Résumé

Ce mémoire se présente comme une anthropologie de la souffrance menée auprès d'une communauté dédiée à la maladie de l'anémie falciforme, localisée dans les régions de Montréal et d'Ottawa. Il explore les rapports entre l'anémie falciforme et certaines dimensions non biomédicales de la vie des personnes atteintes de la maladie, à savoir leur identités noires et le racisme, la stigmatisation culturelle de l'anémie falciforme dans les communautés afro-diasporiques et, enfin, le christianisme évangélique, une confession prédominante au sein de la communauté de l'anémie falciforme. La souffrance partagée à l'intérieur de la communauté de l'anémie falciforme est, en premier lieu, indissociable de l'identité noire, ainsi que de la persistance de la marginalisation raciale. En deuxième lieu, cette souffrance est façonnée par l'histoire collective de migration portée par les membres de la communauté et par la stigmatisation de l'anémie falciforme au sein de leur communauté d'origine et dans les communautés diasporiques. En troisième lieu, la souffrance entourant l'anémie falciforme est étroitement rattachée à l'expérience religieuse évangélique. Si les églises évangéliques peuvent reproduire et intensifier la stigmatisation de l'anémie falciforme, Dieu offre un double salut aux fidèles : la fin de la souffrance et la rédemption grâce à la souffrance. Les promesses divines pour soulager la souffrance et d'enseigner à travers elle permettent aux membres de la communauté de l'anémie falciforme d'espérer la fin de la souffrance – mais aussi de donner un sens à leur vie. Cette communauté émerge donc à la confluence de la foi et de multiples axes d'exclusion sociale qui sillonnent la vie de ses membres. À la base, ceux-ci vivent leur maladie comme une forme d'abandon social. Toutefois, en partageant leurs expériences similaires de souffrance au sein de leur communauté, les participants tissent des liens d'intimité, prennent soin les uns des autres et allègent collectivement leur souffrance. Ultimement, la foi nourrit la communauté, car elle pousse les croyants à œuvrer pour soulager la souffrance de leurs pairs. La communauté de l'anémie falciforme perdure ainsi à travers le partage et l'échange mutuel de la souffrance de ses membres. En ce sens, ce mémoire fait intervenir et relie deux modalités de souffrance qui sont à première vue dissonantes, soit la souffrance sociale et la souffrance rédemptrice.

Cast of Characters[1]

Main characters

Aisha
A "sickle cell mom." She carries the sickle cell trait. Her son has sickle cell disease. The pair immigrated from West Africa three decades ago. She lives in Montreal with her husband and three younger children, but works with a sickle cell patients' association based in Ontario.

Cam
A patient in his early forties. He comes from West Africa. He volunteers frequently for Crescent, a local sickle cell patients' association in Montreal. He has no children and lives with his long-time partner in Montreal.

Emma
A "sickle cell mom." She is a trait carrier. Her daughter is 21 years old and has sickle cell disease. Emma immigrated from Central Africa twenty years ago. She is a single mom and lives with her daughter in Montreal.

Alice
A patient in her mid-twenties. At the start of fieldwork, she had been living in Canada, more precisely Montreal, for nine months. She comes from West Africa. Her family still lives there.

Beatrice
A "sickle cell mom." She is a trait carrier. Her teen daughter has sickle cell. She immigrated from Haiti two decades ago and has been living in Montreal since. She is a single mom and lives with her daughter.

Secondary characters

Yves
The first person I meet when entering the field. He is a sickle cell patient in his early forties. He originates from West Africa. He lives in Montreal and works with Crescent.

Ade
Cam's cousin. He is in his mid-twenties and comes from West Africa. He has sickle cell disease and lives alone in Montreal.

Elie
A patient in her early fifties. She immigrated from Haiti two decades ago. She is married and had a single son who died two years ago for reasons unrelated to sickle cell. She lives in Montreal.

[1] All interlocutors' names are pseudonyms, save the poet Dwayne Morgan. He requested I use his name. In addition, some minor identifying details have been omitted or modified to protect anonymity. Never do I tinker with place of origin or religion, but ever and anon I trace a person's origins to "West Africa" without specifying country or ethnicity.

Tarah
A patient in her early twenties. She was born in Montreal, but her parents immigrated from Haiti and West Africa. She is the only person in her family with known sickle cell disease.

(Severine)
The visiting busybody.

You can live in a home,
And know that something is wrong,
But struggle to prove it,
Or find support,
So you suffer in silence,
Or with a community
Of others who share the same pains,
A cul-de-sac of collective grief.

Apparently,
Grief is our only constant,
And we constantly watch
The homes of our neighbours erode,
Under the pressure of neglect,
And we wonder,
Why no one seems to care about us;
How much suffering is enough?

Maybe,
If we can remove the stigma attached,
To how we've been wired,
We can work together,
Conspiring to inspire
Those from healthier communities
To make donations,
To improve our property value,
But first,
We need to be valued,
By those at the top.

Untranslated excerpts from "Sickle Cell Poem."
Composed and recited by poet Dwayne Morgan at an event this summer.[2]

[2] Included with permission from the author.

Introduction

Breathe in, breathe out.

Breathe in, breathe out.

An inward – pathetically unavailing! – incantation to calm my pounding heart as I ring the doorbell of Crescent, a sickle cell association in Montreal.[3] I wait a minute, wringing my hands, car tires crunching the wet pavement of the busy street behind me. *Breathe in, breathe out,* cries again my mind's frantic voice. The glass door remains locked. My gaze drifts to a paper-size sign fixed to it. Crescent's name is displayed next to a bunch of sun-bleached red blotches I imagine represent sickled cells. *Right address.* I press the doorbell once again, with greater determination.

The door buzzes.

I peel it open and slip into a claustrophobically narrow stairwell. Clouds hang low this afternoon, and dark light seeps timidly through the front door's glass panes. A head peeks over from the doorframe on the second landing. It disappears. Instantly it reappears, puzzlement etched across the man's bearded face.

"Can I help you?" he asks.

I gather word of my invitation to this day's support group meeting has not reached him. I approached Crescent's president to discuss the possibility of conducting research with them last week. He seemed enthused about my interest in sickle cell and encouraged me to attend their next support group meeting. This is what I am here to do. Crescent seems a propitious place to make acquaintance with people who live with sickle cell.

With the quivering voice of a consummate introvert, I introduce myself but neglect my name, stringing together a passable explanation of my research objectives: I would like to understand the pain of sickle cell, I say. The man's eyebrows arch as I speak, but he invites me to come up when my ramblings end.

"My name's Yves, by the way," he says as I climb the precariously steep flight of stairs. "I'm on Crescent's executive committee."

[3] Crescent is a fictitious name.

I arrive on the second floor. “I’m Severine. Nice to meet you.” We shake hands and exchange polite, but uncertain, smiles. Then I follow him down the dimly lit hallway lined by a few open doors. White light and a hum of indistinct voices spill from the first one to our right. When we reach it three steps later I understand this is where support group meetings take place.

Yves beckons me in. Tentatively I cross the threshold to the class-sized room. A large square shape assembled by about eight adjoined tables occupies most floorspace. On the outer edge of the shape are arranged rows of chairs, forming concentric circles that spread outward like squiggly tree rings. Stacks of black chairs are pushed against the rear wall, next to a line of cloudy windows. White walls reflect the overheads’ harsh fluorescence. Squinting, I see that there is space for thirty or forty to sit. Only half the seats are occupied now.

Silence falls upon my appearance.

The sea of moon eyes.

There is still no talk a few seconds later. Meekly I smile at the frozen crowd. My face is getting hot. From the mushrooming half-frowns I take it visitors are a rare occurrence.

“Actually, we can talk outside,” Yves says, stepping back into the semidarkness of the deserted hallway. I follow. “That way you won’t be giving everyone a show,” he adds. A surge of relief washes over me. I laugh with a tremble of giddiness.

He leans against the wall. “So what got you interested in sickle cell?”

The tricky question. I tread gently, reluctant to admit that a strange and purely coincidental concatenation of events has catalyzed this research project. It began with an illness narrative paper written in the context of a graduate seminar, for which I interviewed a family member who lives with sickle cell. Curiosity burgeoned. One thing led to another. The first paper became a second paper and a third paper and a research proposal and now fieldwork.

I opt for a half-truth: “There is very little research about sickle cell in anthropology.”

At which he gives me a look of scrutinizing intensity. “But how do you know about sickle cell?”

“My uncle has it,” I say.

His sceptical eyes narrow further. “Your uncle?”

“My uncle.”

Blankly we stare at each other.

"We're not biologically related," I blurt out to paper over settling awkwardness. "He's from Africa."

He tips his head back, features softening. "Ah, I see."

I then explain that my uncle informed me about Crescent. That is why I contacted its president. I wonder if the latter will be joining us today.

"Yes, he's always here," Yves says. He then tests the scope of my knowledge about different sickle cell types, gauging how much I really know about the disease he himself lives with, before offering a compressed biography of the president's impressive life. "His daughter received a bone marrow transplant, so she is cured – I mean she is still a carrier. You'll probably see her today. But his son died from the disease twenty-five years ago. That's when he founded Crescent."

I grope for intelligent, sensible words with no success. I never foresaw a confrontation with death five minutes into fieldwork, and Yves's casual familiarity with loss throws me off balance. A hollow "I'm sorry" is all I manage.

His lips curve into a grim smile. "You will see that there is history here."

…

This thesis is about sickle cell suffering, the suffering that surrounds sickle cell disease. They are not equivalent. Sickle cell disease, also known as sickle cell anemia, drepanocytosis,[4] or more colloquially sickle cell, is a single-gene disorder of hemoglobin, a protein in red blood cells. Pattern of inheritance is Mendelian, or monogenic. This means an individual has to carry two recessive sickle cell genes (hemoglobin S) to develop the disease.[5] Those who carry one gene are called trait carriers. They can pass the gene to their biological children and experience no symptoms. Sometimes very few. The sickle cell community I know is a medley of disease-carrying and trait-carrying individuals. "Patient" is the term employed commonly to refer to persons with the disease. The terms "parent," "sickle cell mom (or dad)," and "carrier" are utilised loosely with reference to trait-carriers. I follow the community's terminology.

[4] From the Greek *drepanon*, meaning sickle or scythe.

[5] Very few diseases are strictly Mendelian, or directly passed down from parents to offspring through a recessive trait (Chakravarti 2021). Included in the small pool of Mendelian diseases are cystic fibrosis, hemophilia, and Tay-Sachs disease, among more arcane ones.

"Once the doctor had explained sickle cell to me, I cried and cried and cried," says Emma, a sickle cell mom. Sickle cell's hallmark symptom is pain, excruciating pain, pain without relent, "the pain is impossible." The pain is, according to a patient named Elie, "its own thing." When patients are exposed to deoxygenating conditions such as high-altitude travel, great cold, excessive heat, exertion, dehydration, stress, and sleep deprivation, their red blood cells morph into little half-moons. Those sickle-shaped kernels of pain are not as squishy and bouncy as round ones. They are liable to causing traffic jams in capillaries and small blood vessels. Blockage can occur everywhere blood travels, including the brain, the eyes, and the heart. This is called a pain crisis.[6] "When you're in crisis, it's a pain that…I don't know if it can be described. It's like two sensations," Elie tells me. "Either we're being crushed by a truck, and the truck rolls back and forth on our bones. Or it feels like someone is hammering our bones. It cuts your breath. It's lacerating pain. It fluctuates. It can start in one spot, and in an instant you realize it hurts everywhere. It can take a week to control."

Elie goes on, "People don't seem to understand that I can die every time. They think that you have a crisis, you go to the hospital, and you make it out. But no. Some die." The most severe pain crises are fatal if left untended. Crises do not all require hospitalization, however. Ninety percent are treated at home with an array of palliatives that ranges from ibuprofen to morphine (Rouse 2009). Beyond crises, sickle cell impedes the organism insidiously. Chronic oxygen deprivation notwithstanding, sickled cells are sharp like blades. With time, they damage organs through which they travel. Premature osteonecrosis and renal insufficiency are not unexpected. Chronic pain quickly joins the fray. And those warped blood cells are brittle. Their continual break-down saturates the macrophage system (white blood cells' work station) and generates iron-deficiency anaemia. Susceptibility to infections and concomitant septicaemia is high as an after-effect of repetitive pain crises. In Canada, patients' life expectancy floats in the mid-fifties, according to health practitioners I met. In sub-Saharan Africa, it sinks to the early forties.

Like most non-European states, Canada does not universally screen for sickle cell country-wide. Numbers are therefore estimates. As of 2024, Canadian Blood Services estimates national prevalence to be over six thousand. About six hundred live in Montreal. A drop in the ocean.

[6] I employ my interlocutors' words to write this rendition of sickle cell. The information provided is biomedically supported (Kato et al. 2018), but I prioritize patients' linguistic practices. I borrow the words "half-moon," "traffic jam," "squishy," and "bouncy" from various patients.

Globally, sickle cell impacts eight million. Sub-Saharan Africa bears the greatest disease and mortality burden (Tusuubira et al. 2019). On average, one in ten persons of African descent carries the sickle cell trait, and one in three to four hundred carries the disease (Kato et al. 2018). Such clustering is widely hypothesized to occur because the sickle cell trait affords protection against malaria infections (Packard 2007). Other populations, such as those of India and the Mediterranean and Persian Gulf basins, indigenously developed the same genetic resistance against malaria (Packard 2007; Piel 2010). Therefore, the sickle cell trait cannot be traced to Africa only. Its concentration among populations of African descent is non-exclusive.

Among the people I know, the management of chronic and acute pain alone is a heavy burden. Sheer exhaustion is an important driver of so-called treatment non-compliance, or patients' neglect of their regular medical appointments. The vast majority of patients are prescribed a mixture of opioid painkillers as well as a low-grade chemotherapy drug, hydroxyurea (nicknamed hydrea). In short, hydrea diminishes the incidence of pain crises. Side effects include nausea and migraines. Hydrea also engenders temporary infertility. However, many people in the sickle cell community fear lifelong infertility. Though unproven biomedically, the fear of permanent infertility induced by hydrea remains a source of profound anguish for the patients and parents I know. "As Black people, it's very important for us to reproduce," a sickle cell mom named Aisha tells me, with reference to hydrea. "We believe we are born on this earth to have kids." Patients' fertility is halted temporarily when taking daily hydrea capsules. Fertility blooms again as soon as patients discontinue hydrea. Many in the sickle cell community still worry hydrea will, in Aisha's words, "make them individuals who will be childless." I expand on the issue in the first chapter.

A caveat. While I speak of sickle cell as a singular entity, it is a protean disorder that encompasses a range of subtypes which vary with genetic makeup (Ballas 2005). Under the Mediterranean sun, for instance, it mingles with beta-thalassemia. A person can possess both sickle cell and thalassemia traits. The resulting disease manifests as sickle cell. Sickle-cell-beta-thalassemia tends to present milder, but nonetheless severe, symptoms. Many other subtypes have sprung up around the world. This is to say that, while severe pain is universal across subtypes, experiences differ. So do treatments. The overwhelming majority of patients are prescribed hydrea and strong painkillers (i.e., ibuprofen, Dilaudid, and morphine), and most spend considerable time at the hospital. However, hospital visits have different purposes. Some

patients require frequent blood transfusions and red blood cell exchanges; others not. Some are hospitalized due to pain crises every two months; others only every other year. Some suffer from osteonecrosis and require hip replacement surgery at twenty-five; others never will. Many suffer from a variety of co-morbidities like asthma, depression, leg ulcers, chronic renal disease, or acute chest syndrome (Ramsey et al. 2022). These sickle cell complications necessitate different treatments. Since these co-morbidities are ramifications of poor circulation and accretive organ damage (Ramsey et al. 2022), they accumulate with age "insidiously," as a nurse working in a sickle cell treatment centre puts it. "Everything comes down to sickle cell." Everything biomedical, perhaps, but, needless to say, not everything is biomedical. Suffering does not come down strictly to sickle cell disease for the people of the sickle cell community.

the sickle cell community

As intimated in the introductory scene, the field revealed itself in spring of 2024 when I crossed Crescent's door, a local sickle cell patients' association in Montreal. Crescent is where I conducted the bulk of fieldwork, but I also dabbled in a second association in Ottawa. I had not planned to stray from Montreal. Having said that, Cam, a patient, invited me to an event organized by this second association in Ottawa. Fear of missing out prevailed. Since I spent but fleeting time in Ottawa, I leave the second association unnamed to prevent confusion.

In the words of volunteers I met, these sickle cell associations work toward "improving patients' and their families' quality of life" by "forging a sense of belonging" and opening a space "where they can be heard." Crescent's website indicates that one of its primary objectives is to "fight the isolation and exclusion of patients and their families." To this end, multiple activities, including support groups, are organized to provide a space where people can share experiences. The associations also offer financial help to patients, particularly uninsured newcomers, who are unable to afford costs incurred by medication and frequent hospital visits. At a baseline, then, these two patient associations can be understood as biosocial groups, or social webs spun around shared biological predicaments (Rabinow 2005). In the advent of new genetics, people who share certain kinds of biological vulnerability brought to light by new bioscientific knowledge, such as genetic traits, often form social groups (Rabinow 2005). These collectives meet to share experiences with their

biological condition. On this simple level, sickle cell associations are instances of the biosocial, to the extent that all participants possess the sickle cell trait.

In parallel, biosocial groups lobby for their core diseases (Novas 2006; Rabinow 2005). They advocate for greater state funding into biomedical research in hopes of hastening the development of therapies and cures (Novas 2006). In mobilizing networks of scientists and policymakers, patient activists influence the direction of science. Advocates also raise public awareness about their diseases. They try to shape public narratives about their afflictions, and also to draw societal attention to their suffering (Novas 2006; Rouse 2009). The two sickle cell associations I know engage in such activist efforts. On the one hand, they raise awareness about sickle cell screening and the constant need for blood donations within Black communities. Their awareness-raising efforts are concentrated within Afro-descendent communities, on account of high levels of illness stigmatization therein. Occasionally, they visit medical schools, or pen opinion pieces in mainstream news outlets, to magnify public concern around their suffering. On the other hand, they mobilize political actors (e.g., members of parliament such as health ministers, and senators) and scientific communities to pay greater attention to their suffering, and fund biomedical and pharmaceutical research. Their goals are to propel the discovery of new treatments and a cure for sickle cell, according to their presidents. By funding and mobilizing policymakers, blood agencies, health professionals, biomedical researchers, and pharmaceutical companies such as Pfizer and Vertex, sickle cell associations hope to orient the production of bioscience toward sickle cell. The sickle cell community actively labours toward the realization of concrete hopes for a world rid of sickle cell suffering.

This thesis is not a study of the sickle cell associations themselves, nor does it concern itself primarily with sickle cell advocacy. More accurately, Crescent and its Ontario counterpart form the context within which fieldwork has unfolded. Attending their events, and thereby meeting people who suffer from sickle cell, has allowed me to discover a rich social world called the sickle cell community. This community is a network of relationships orbiting around patient organizations. As is generally true of human community (Nancy 1991), the sickle cell community possesses no solid frontiers. Some employed the term with reference to the sociality revolving around Crescent. Many expanded its scope to Quebec, and others to Canada. A few further pushed its boundaries outward to the global scale. Therefore, one could say I visited only a corner of the indeterminately wider sickle cell community.

Throughout the thesis, I use the term ‘sickle cell community’ to refer to the network of relations revolving around sickle cell within my reach. When I allude to the sickle cell community I have in mind the sociality circling primarily Crescent but extending to the Ottawa region. The two regions are interconnected by virtue of geographic proximity. Some patients and activists shuttle between them. French dominates interactions within Crescent, but French and English (as well as a polyphony of Haitian Creole and various African tongues) coexist in Ottawa. I concede this narrow strip of land represents a fabricated enclosure. Communities are non-monolithic and without essence, Nancy (1991) reminds us. They do not name homogeneous totalities but open spaces of interpersonal relations, ever in flux, incomplete (Nancy 1991). Because communities resist geographic incarceration or conceptual captivity (Nancy 1991), it is conceptually dubious to congeal them into realized entities with solidified demarcations. I elaborate my mobilization of community as an analytic later on. For now, it should suffice to note that I do not treat the sickle cell community as a fixity. Still, to combobulate the conceptual fluidity, I find it helpful to seal the sickle cell community inside the Montreal-and-Ottawa bubble. The area embodies the geographic scope of my fieldwork. It is home to the community I met through the serendipities of fieldwork.

serendipities of fieldwork

During the warmer months of 2024, I foraged for nuggets of truth from those who live with sickle cell – patients and their parents. I mingled with them foremost at Crescent’s events and activities, and prolonged conversations with some afterwards. That is to say, I conducted participant observation with the sickle cell community. Trailing Tim Ingold’s footsteps, I understand participant observation quite simply as a “way of participating attentively” (2017, 23) in people’s mundane lives. As such, I attended: fundraising events such as a gala and a poetry reading night; support group meetings; a day-long symposium in Ottawa; a breakfast with activists, patients, and senators; various educational webinars; a picnic organized by Crescent; a paediatric-to-adult healthcare preparation event; and a four-day camping trip with patients and their families, all while paying close attention. The many informal conversations I was fortunate to have there, some with people I saw multiple times and others with new faces, have yielded great insight. Sickle cell events were organized

sporadically. Fieldwork was, therefore and regrettably, not a full-time immersion in the community. Since it was a part-time undertaking, I stretched my time in the field from early May to late September, for a total of five months.

In the intervening hours, I spent many muggy afternoons and more sultry nights tagging along one patient as she went about her life. Her name is Alice. We made acquaintance in May during a support group meeting, as she attended most events Crescent hosted. (We get to know her in the second chapter.) In addition, I conducted seventeen interviews with patients, their families, and medical practitioners working in a sickle cell treatment center in Montreal. Typically interviewed were people whom I had met during events. I grew acquainted with others over the summer. Interviews with patients and caregiving kin were long: two, three, four hours. I often lingered afterwards, drawing out conversations into late afternoons and early evenings. And, as I rubbed shoulders with those same people all summer, I was able to situate their stories in the small world of the sickle cell community.

On account of such marked engagement with the human voice, methodology consists of a mixture of participant observation and illness narratives.[7] I elicited people's illness narratives principally during interviews, and collected or completed others through participant observation. During interviews, I spoke little. They are quite chatty, the people of the sickle cell community. They needed only occasional prompting. I usually opened the exchange by asking about their life stories in relation to sickle cell, which allowed people to cover themes they found most important. I then further explored these tangents with storytellers as they took form, or circled back to them later on.

I always carried a list of themes I wanted to cover. Most had already surfaced in previous interviews and sickle cell events – antiblack racism, sickle cell stigma, immigration, family, faith. People often brought up many of these on their own, but I would ask about them if they did not. My implication in people's narration thus assigns me a mediative role in their composition (Crapanzano 1980). True, I intervened spasmodically, but stories took form through the dialogic encounter. After all, I nest my fieldwork under the methodological eave of participant

[7] My methodological recourse to illness narratives life rests on a number of Judeo-Christian assumptions about the centrality of narrativity to self-experience. Robert Desjarlais (1994) and Galen Strawson (2004) remind us that to narrativize life is a historical possibility, and not a universal given. My resort to narratives is predicated on assumptions of unity of self, individual agency, reflexive interiority, and personal transformation. This is not to pre-emptively discredit my intellectual endeavour. Rather, I wish to lodge it within a specific way of thinking, so as to render transparent the self-referential aspects of research.

observation. Portrayals of life emerging during interviews are, in this participatory sense, negotiated realities (Crapanzano 1980). My encounters with people moulded the very illness narratives I chased. That does not, however, mean narratives boil down to encounters. The unprompted resurgence of themes across stories seems indicative of broader truths about sickle cell.

Illness is a "call for stories," writes Arthur Frank (1995, 53). He, like Arthur Kleinman (1988), defines illness narratives as personal tales sufferers craft in an effort to arrange illness experience in a meaningful or coherent way. Narratives are invaluable tools for medical anthropologists, as they constitute important means through which individuals communicate what matters in their lives (Frank 1995; Kleinman 1988). Importantly, building blocks for narratives are excavated from personal experiences that are situated within larger historical and cultural contexts. Narrators do not exist apart from social worlds. At the same time, narratives gathered among similar people are not mere replicas of each other and of the social world in which they are composed. As I hope will become lucent, narratives I reaped vary in accordance with the vicissitudes of people's lives while being in conversation with others in the sickle cell community. Individual narratives also insert themselves within much larger and culturally salient narratives of suffering, such as antiblack racism and Christian salvation. This is all to say, remarkably similar themes emerge in people's storied accounts of sickle cell, but espouse the textures of singular lives.

My enquiry inclines toward the "social" end of the spectrum, as opposed to the "individual." While I sometimes dip a toe into people's inner lives, I am concerned foremost with their narratives' embeddedness in the world. I turn my analytic gaze on elements of their stories that speak to larger phenomena (i.e., racial discrimination, culture and sickle cell stigma, faith) and surface in many people's accounts. One might say I work to create a panoramic portrait of the sickle cell community. Of course, to prioritize commonalities runs the risk of sublimating singularities into a simulacrum of totality, thereby flattening individuals into two-dimensional silhouettes devoid of agency (Gandsman 2022; Levinas 1998). I am aware of these perils and mourn my sacrifice of intrapersonal depth on the altar of the broader story. Yet, in my view, the latter should be assembled before the infinities held within individuals can be roamed properly. Granular explorations of illness narratives, and more pointed considerations of individual agency, are left for later venues.

Of note is that illness narratives are not polished accounts assembled retrospectively. They are spoken as they are lived, under perpetual remaking, and, in turn, shape how authors live illness (Frank 1995; Kleinman 1988). Narratives are in a ceaseless process of revision, sometimes fragmenting even as they reach for coherence. "Mediums of being" (Frank 1995, 53), they serve as ever-changing guides for present actions and future expectations. Relatedly, illness narratives are not repositories of cold facts but of "deeper truths" that should be understood in the context of their authors' fluid existence. Deeper truths that come to life through narratives are not strictly factual but enlarge reality, create possibilities for action, and establish meaningful connections between remembered past, present, and imagined future (LeGuin 1989). Illness narratives, then, are fictional. Fictitiousness does not presuppose falsehood, though. As the saying goes, fiction is another way of telling the truth about the world. Seen as true fictions, illness narratives portrayed in the thesis are not timeless depictions of sickle cell suffering. On account of the ongoing flux of human life, I cannot assume that what I heard and witnessed one summer always takes place. I offer but a momentary glimpse.

Which leads me to the matter of ethnography. I hesitate to consecrate my research ethnographic. Slowness weaves the warp and weft of ethnography. Worming one's way through the field, cultivating relationships, building trust, devoting oneself to the minutiae of life: these take time (Biehl 2005). The people of the sickle cell community and I brushed against each other. We could not nurture the patient intimacies integral to the art of ethnography in one short season. Analogously, steeping in the entire worlds of those we study with is part and parcel of ethnography. Meditating on the anthropological pursuit, Ari Gandsman (2022) suggests that the roominess of small lives probed during interviews should not be scrunched within the space of the individual. That roominess expands onto a universe of relationships. The anthropologist's duty, he reminds us, is to stitch the little truths surfacing during interviews to their larger context of emergence. Only then can we gaze into the depths of human existence.

I apply myself to contextualising individual stories in relation to the sickle cell community that envelops them by travelling back and forth between microscopic and panoramic views. However, I am unable to adequately embed narratives within the larger social terrain of people's quotidian lives, with the exception of Alice. For the most part their lives outside the sickle cell community elude my reach. Could the clock be rewound, I would dedicate greater energy to accessing the humdrum of ordinary life, for last summer I could not fold into the hearts of those

in the sickle cell community. So, because analytical gaps bestrew this thesis, because narrative enquiry affords vicarious knowledge of people's experiences, and because the language with which stories are told is never transparent (Blanchot 1995; Crapanzano 1980), ethnography is understood best as guiding aspiration than practice. My comprehension of sickle cell pain and suffering does not ripen to fullness.[8]

pain and suffering

"The community suffers," a sickle cell mom named Aisha tells me. This thesis may recount the sickle cell community's suffering, but that was not the initial plan. I initially whittled down analytical focus to the pain of sickle cell. Upon entering the field, my mind was fixed on discovering how, if at all, patients could find meaning in their pain. In early interviews and informal conversations, I tried to prompt narratives that would hand me the meaning of people's pain on a silver platter. In no time did my plan crumble. People showed little interest in my research interest. To be sure, no taboo loomed over pain. If asked directly people would offer thoughtful responses. Then, without fail, they would shift the topic of conversation to other matters that manifestly made for a more interesting chat. They liked to discuss illness much more broadly and dwelled on certain themes: racial discrimination, sickle cell stigma, and faith.

I lent ear to their truths, and began broaching these topics in later interviews. New threads of enquiry could thereby surface, threads that have come to weave this thesis. In *Veiled Sentiments,* Lila Abu-Lughod (1986, 23) tells of the "non-directive approach" her fieldwork among Bedouins took. She was unwilling to conduct structured interviews and pursue questions forcefully. Doing so would have impeded her ability to elicit her interlocutors' conceptions of the world freely. She elected to shape her enquiry around matters that her interlocutors found most interesting. Granted, I have embraced this non-directive approach rather accidentally. It nonetheless led to the realization that my original

[8] Therein lays my fieldwork's hamartia, in the dual sense of fatal flaw and fatal lapse in judgment. Neglecting to seek greater access to people's lives beyond the sickle cell community – and to people who do not partake in the community – cripples my ability to ascertain how much people's narratives were shaped by their interactions with the community itself. Would patients who never participate in the community emphasize the same themes as those who regularly do? Would they have different stories to tell about sickle cell stigma, for instance? I am confident faith would play an equally prominent role in their stories of suffering, but doubt creeps upon me where antiblackness and stigma are concerned. The reader should be mindful that this thesis is nestled securely within the sickle cell community.

focus on pain was too narrow, and, by the same token, made way for the discovery of a kind of suffering that boils over pain.

People of the sickle cell community generally articulate pain as suffering. When speaking of their pain, many would use the words pain and suffering interchangeably. This noted, pain and suffering are kindred, not synonymous, notions. Relating to pain as an experience of suffering is not universal, physician-anthropologist Scott Stonington (2015; 2020) learns through practicing palliative medicine in the United States and Thailand. A few patients and interlocutors in both locations make a clear distinction between end-of-life pain and suffering. For some patients, seeking to break out of pain, or unfulfilled desire, is what produces suffering. To aggressively treat pain with opiates might then yield greater suffering. From this, Stonington concludes that alleviating pain does not always alleviate suffering in the palliative ward. "I have changed my approach to pain management," he says. "I no longer ask 'Is this patient in pain?' Instead, I ask 'How do I relieve this person's suffering?'" (Stonington 2015, 1389). Pain, then, is not invariably a source of suffering. To be clear, Stonington does not argue that pain and suffering never coincide. Rather, they are not universally coterminous. For pain to be related to as suffering, one must reflect on pain as such. There is a kind of existential reflexivity involved in the experience of suffering that is not preconditioned by pain.

Unlike suffering, pain has a distinctive visceral immediacy about it. On the level of embodied experience, it is unshareable. One's pain remains foreign to the witness, ever vulnerable to suspicion, Elaine Scarry (1985) writes in her classic treatise on the isolating power of pain. Pain is a centripetal force that yanks its victim to the immediacy of their body because, she contends, it possesses no referential content. It is not *for* anything. It designates only itself, an otherness within the body. Pain beggars communication and representation. It is the quintessential antisocial experience. By remaining experientially unknowable, unverifiable, to the witness and drawing the person in pain inwards, pain cracks open a faultline between them, rends its victim's social world.

A few anthropologists have come to question Scarry's grim portrayal of pain as a purely isolating force. Clinical ethnographies of cancer wards (Banerjee 2020; Livingston 2012) and pain clinics (Buchbinder 2015) have thrown light on the relationality of pain. Pain, naysayers contend, is a social experience, since it forges relationships of care and sometimes compassion. It might be tempting to view the sickle cell community principally as an instance of this kind of

pain sociality – a network of relationships of care leafing out from patients' pain. This perspective may hold a kernel of truth. Those in the community did care for each other's pain. But I do not consider physical pain by itself to be the issue of greatest importance in the community. It animated few conversations relative to other topics. Pain was mentioned, of course. Every so often people shared pain-relieving tips and tricks to others, yet seldom was the matter dwelled on. Moreover, I am disinclined to think the kind of caregiving I witnessed in the community betokens an experience of sickle cell pain as social. The patients with whom I interacted during mild pain crises seemed to close in on themselves. Their pain appears to be immured within them.

When Aisha alerts me to her community's suffering, she is referring to an experience that includes but overspills pain. In my estimate the sickle cell community is composed of patients and trait-carrying parents in equal parts, and yet, as the chapters will try to bring to light, caretaking parents suffer from sickle cell. Greatly. Beyond pain and physical sickness, sickle cell suffering includes the experience of social isolation resulting from marginalization, the anguish of sudden or premature death, everlasting grief for intermittent losses of community participants, skewed life opportunities, fear of infertility or maternal death, and guilt for having passed down the disease. Suffering is a word that was commonly employed to characterise these nonpainful experiences, which afflict patients and caretaking parents. "Suffering spills to the patient's family psychologically, emotionally, financially, just to name a few, because they care about the child," one sickle cell mom tells me.

Thus, just like pain can exist in the absence of suffering (Stonington 2015; 2020), suffering can exist in the absence of pain. It does for sickle cell parents. My view is that suffering entails existential distress, whereas pain does not necessarily. Following the philosophy of Levinas (1998), to whom I later return, suffering can be thought of as an experience of undergoing that is existentially disruptive. Suffering tears the fabric of one's world: imperils the integrity of one's own identity, rips one from one's social circles, disrupts one's life trajectories, and risks shrinking life's meaning to absurdity (Wilkinson & Kleinman 2016). Pain is experienced as suffering once it is reflected on and articulated, or given form, through existential anguish. People of the sickle cell community experience their pain, as well as broader "nonpainful" dimensions of their illness, as suffering.

When I mention suffering or "sickle cell suffering," I include sickle cell pain as well as those broad experiences of existential distress listed above, as do my interlocutors. Patients and caregivers cannot, of course, suffer in a selfsame manner. Beside parents' occasional guilt for disease transmission and lack of access to sickle cell pain, high mortality in the community breeds greater distress among parents than patients. The intermittent deaths of patients serve as memento mori for their kids' shortened lifespans, or plunge them into haunting memories of their own children's deaths. They must also helplessly endure watching their children writhe and scream in pain during the more violent crises. Patients and parents seem to suffer from social isolation, and mourn a life without sickle cell, to the same degree. Sorting parents' and patients' suffering is not intended to hierarchize it. Suffering is incalculable and, therefore, incomparable. I only parse patients' and caregivers' experiences to familiarize the reader with their at times differing, at times parallel, experiences. Parents and patients equally articulate their sickled lives as suffering. That is what matters.

Inevitably, my cogitations about suffering carry those of medical anthropologists whose legacies have infused my training. One notable intellectual forebear of mine is Arthur Kleinman. As Kleinman (1988; 1997) suggests, suffering – especially when illness is concerned – is relational. Illness, contrary to the biologized notion of disease, is the meaningful, culturally shaped experience of embodied distress that is connected without being shackled to biology. Crucially, illness is a form of suffering that is lived by patients *and* caretaking members of their social network, it is transpersonal, it spiders out across patients' proximate social worlds. In contrast to pain, then, the experience of illness can be shared. This means that when it manifests as illness (but not only), suffering is a social experience. It comes about through "transpersonal engagements in a local world: a family, a network, a neighbourhood, a community" (Kleinman 1997, 326). This view of illness as relational – the flux of illness is lived, always, in interconnection with others and the world – threads the thesis.

If illness can strengthen interpersonal ties, so does it contain the potential to rupture community and family networks, Biehl reminds us in *Vita* (2005). His account is grounded in the tiny context of Catarina's life. Still, his insistence that serious illness engenders family abandonment is applicable to sickle cell. Sickle cell has severed family relations for some people in the sickle cell community. It is stigmatized, as we will see. Social isolation from kin and community networks ensues. But *caretaking* family members who partake in the sickle cell

community, typically mothers, live sickle cell interpersonally. “Sickle cell is a family affair,” Aisha tells me. Many parents in the community refer to sickle cell as “our disease,” and their children’s crises as “our crises.” A sickle cell mom named Emma says, “when my child is in pain, I’m the one who suffers.” Emma has also explicitly advised me to broaden the scope of my research to include trait carrying parents. “You need to talk to us parents,” she says. “Our kids don’t know anything. We’re the ones who know suffering.”

Where people of the sickle cell community find themselves cast aside from their wider social networks, they develop strong social connections with one another. For instance, while caregiving parents’ bonds with their sick children have solidified, they suffer social exclusion from their proximate communities. Sickle cell is thus a profoundly transpersonal “family affair,” in that it encompasses caregivers, while it ruptures family networks at the same time. Because sickle cell suffering is interpersonal – at least where the caregiver-and-patient dyad is concerned – I do not restrict analytical purview to patients.

There exists another way in which we might write of suffering as social. This second meaning to the notion of social suffering is simple, but its simplicity does not chip away at its worldly prescience. Its usefulness lays in drawing attention to the injuries inflicted by social forces upon human experience (Kleinman, Das, & Lock 1997; Wilkinson & Kleinman 2016). In so doing, the concept of social suffering collapses artificial distinctions between various realms of human life, such as the political, the economic, the religious, the cultural, and, of no surprise, the medical. The analytic scope of social suffering covers all of them. Here the important insight guiding my thinking is that medical suffering should not be sundered from wider dynamics of harm. The skewed distribution of bodily suffering maps onto the geography of social injustice, an overlap which, as will soon become clear, the sickle cell community is keenly aware of.

As alluded to in my theoretical toe dip into illness narratives, large-scale arrangements do not determine statically the vicissitudes of everyday suffering. Overarching social forces come into existence in specific contexts and in even more specific individual lives. Embodied experiences of affliction are lived within the whirl of meanings engulfing individuals and communities. Styles of suffering are historically and culturally specific, which means that they are shared within communities (Kleinman, Das & Lock 1997). At the

risk of wheeling out vapid wisdom, experiences of suffering, and articulations of experience as suffering, are far from universal.

Ethnographic research has mobilized social suffering to examine the embodiment of deleterious social conditions in various contexts. I share with proponents of social suffering the belief that examining illness, including sickle cell suffering, throws into relief the social world. This critical theoretical position can be tied to four ethnographies that have exerted themselves upon my own thinking: Paul Farmer's *Aids and Accusation* (2006), Seth Holmes's *Fresh Fruit, Broken Bodies* (2013), Philippe Bourgois & Jeff Schonberg's *Righteous Dopefiend* (2010), and Nancy Scheper-Hughes's *Death without Weeping* (1992). The paramount conclusion that leaps out from this body of scholarship is that the poor and marginalized bear the brunt of suffering. Stated baldly – euphemistic politeness would mask the bare truth – they are sick and die more. Whether among poor Haitians, Mexican migrant farmworkers, itinerant heroin users in San Francisco, or poor mothers in Northern Brazil, instantiations of structural violence are the main drivers of suffering. As a reminder, these medical anthropologists mostly draw from Paul Farmer's (2003) reintroduction of the concept of structural violence in *Pathologies of Power.* He refers, in simple terms, to structural hierarchies and inequalities that are embodied as suffering, sickness, and death.

People of the sickle cell community understand that their suffering does not flow strictly from disease, but from the entanglements of sickle cell with the social world. From the theoretical perspective of social suffering, which coincides in some part with that of the sickle cell community, improving health demands that one tackle such large-scale arrangements. In the community's experience, antiblack racism is one structural social force conditioning sickle cell suffering. Sickle cell stigma would also be a social force perpetuating sickle cell suffering, though a more ambiguous, less structural one. Sickle cell stigma seems to hang at the outer edge of social suffering, as it is not a clear incarnation of structural violence. It lives *within* their home and diasporic communities. Despite not being closely related to traditional modalities of socio-economic inequality, I nestle sickle cell stigma under the theoretical canopy of social suffering. It is of the social world.

This said. Sickle cell also entwines with a parasocial world people of the sickle cell community inhabit. It is parasocial, or adjacent to the social world, because it straddles material and immaterial, immanent and transcendent. The framework of social suffering ends where

God's sovereignty begins, in the parasocial world of faith. That people of the sickle cell community reside at once in social and parasocial worlds means that social suffering provides partial theoretical auspice for my ruminations on sickle cell's alloying with the world. Sickle cell suffering is of social and parasocial sorts alike, being configured by a perplexing combination of social arrangements as well as God's hand. As we will see, theories of social and providential suffering themselves entangle in the sickle cell community.

the entanglements of sickle cell

Launching from this basic theoretical overview, the remainder of this thesis teases out the entanglements of sickle cell disease with the social and parasocial worlds the people of the sickle cell community inhabit. In furtherance of this goal, I analyse principally their explanations for sickle cell suffering. In other words, this thesis grapples in large part with the "why" dimension of suffering, where sufferers plunge into an eddy of existential interrogations regarding the causes of misfortune. I have described suffering as an undergoing that is existentially disruptive. To undergo presupposes passivity (Levinas 1998). Here passivity is employed in its grammatical meaning of the passive tense. It does not refer to an unresistant acceptance of one's lot, or the reverse of agency. Rather, the passivity of suffering indicates that suffering is not self-willed. What passivity implies is that sources of suffering are typically searched for, and subsequently located, outside the suffering self. Hence the reflective, outward quest for understanding suffering's origins upon which sufferers embark: why, why, why.

Suffering hurls people into a search for answers in which they wrestle with the weight of the world, the hauntings of history, the social and parasocial worlds they inhabit (Wilkinson & Kleinman 2016). By itself, biomedicine poorly helps people make sense of their suffering. It is, in fact, infamous for reducing illness, this infinitely complex experience, to biology (Kleinman 1988). In view of biomedicine's explanatory poverty, people turn to the world beyond biomedicine when seeking answers to the "why" question. So with the sickle cell community. Indeed, its people trace their suffering to three social and parasocial forces. They are: antiblack racism, the prevalence of sickle cell stigma in their home and diasporic culture, and God.

Attending to people's answers to the "why" question will, perhaps predictably, touch on the "how" dimension of illness. While they are not always synonymous, devoting ourselves to people's explanations for their suffering cultivates our understanding of how their illness plays out. That is why I expand analytical scope to the entanglements of sickle cell with the world, rather than restricting analysis to their explanations for suffering. People's answers to the "why" question betoken sickle cell's intermixing with the non-biomedical world. They point to the three ways in which the social and parasocial world shape their experience of illness, beyond their explanations for suffering. Because, if they understand sickle cell suffering to be caused by antiblackness, sickle cell stigmatization, and God, their experiences of illness are shaped by their blackness, cultural belonging, histories of migration, and relationships with God. These dimensions of illness are twined, but not coextensive, with their three explanations for suffering.

The first answer to the "why" question circulating in the sickle cell community is antiblack racism. Their experience of sickle cell is inextricable from the ongoing violence of antiblackness. People of the community trace their suffering to antiblack racism, and live sickle cell in the wake of transatlantic slavery. They understand themselves to be Black in an antiblack world, and their suffering to result from antiblackness's iron grip on medicine. As we will also see, sickle cell becomes tethered to community participants' blackness in ways that the conceptual and historically contingent framework of antiblackness only partially accounts for.

Second, their suffering is indissociable from the prevalence of sickle cell stigma in sub-Saharan Africa and the Caribbean, as well as their diasporas. Sickle cell is highly stigmatized in their communities of belonging, and people trace their suffering to the tenacity of this stigma in their culture – a thorny word I will justify in due course. Indeed, the people of the sickle cell community have a strong cultural affinity with each other, which they map onto their shared blackness. Thus, sickle cell is entangled not only with cultural stigma, but with the tropical culture (their term) of community participants. This is to say, sickle cell folds into sufferers' similar histories of migration, sense of cultural belonging, and Afro-descendance.

Third, sickle cell welds with faith. The Holy Ghost is palpable the sickle cell community. It hovers about the bevy of evangelical Christians residing in its midst. Evangelicals identify God as the purveyor of individual suffering. However, the alchemies of sickle cell with the evangelical faith achieve something beyond explaining suffering. As I strive to convey, evangelicals pursue remarkably intimate relationships with their fundamentally good and

omnipotent God. Through this relationship, they redeem their suffering, kindle salvation, find purpose to their suffering. Faith's entwining with sickle cell might thus be better understood as transformative than explanatory.

When braiding together these different modes of entanglement, we may discern sickle cell suffering taking shape at the junction of intersecting axes of dislocation from collective life. The people of the sickle cell community understand themselves to be neglected by medical institutions because of antiblack racism; repudiated by families and ostracized by home, diasporic, and religious communities of belonging because of stigma; and estranged from Canadian culture. They see that their suffering goes unrecognized and that their social existence, or meaningful participation in collective life, is imperilled.

Cutting through this darkness, one parasocial being promises never to negate their suffering, never to forsake them: God. God, who promises to save them both *from* and *through* suffering. God, who transforms sickle cell suffering for the better by nudging believers to enlist it into the telos of salvation. So if I have described sickle cell suffering as including experiences of isolation, grief, fears of infertility and mortality, skewed life opportunities, and guilt, in the sickle cell community these experiences assume added specificity. They blend with similar experiences of racial discrimination, blackness, cultural marginalization, histories of migration, and faith.

Serendipitously, attending to the entanglements of sickle cell and the non-biomedical world breathes life into a story of community. Sickle cell gets entangled with the world in strikingly similar ways for the people of the sickle cell community. Their suffering mirrors each other's. They then find their suffering fellows within the social abyss wrested open by converging forms of social exclusion, resulting from sickle cell's alloying with the social world. I have come to think that the commonalities of suffering permit intimacies that boil over common genetic disease. Ties of coexistence are created through the sharing of similar illness, similar suffering.

a tale of community unlocked

I lend the language of community to this second story, as opposed to biosociality, because the latter levels analytical gaze on common biological predicament. Biosociality fixes genotype at the centre of enquiries into illness socialities. Community, which names a

relation of sharing, does not. A more capacious analytic, it broadens the scope beyond the sickle cell gene. (I flesh out my conceptualization of community below.) Resorting to community allows me to avoid stretching the biosociality concept to disfigurement. That people of the sickle cell community have in common much more than genotype will transpire in no time.

Thinking with community also represents an effort to let people's "arts of existence" (Biehl 2013, 574), or theorizations of their lives, stimulate my own. They articulate their existence as communal, live their suffering in community. The sickle cell community is peopled with individuals who do not only share sickle cell disease but who, in their words, "feel what they feel," who "truly understand them," who "share the same pains" and "share experiences." I once ask Tarah, a sickle cell patient in her early twenties, why she attends Crescent's activities on a regular basis. In her words: "I go because it's a community that understands me, and people outside don't understand me. I also like when people share their perspectives so that I can learn about their experiences, because everyone is different." She breaks off and then resumes her thought: "So I feel…I feel at home." I hope the chapters will illustrate that this sense of feeling understood – of being at home in the community – buds forth from similar experiences of illness, and not strictly sickle cell disease.

Echoing Tarah, a sickle cell mom named Emma reminds me that no uniformity of experience is to be found in the sickle cell community. One day, we chat on a paddleboat and she says: "Crescent isn't the disease. Each person has sickle cell, but it looks different on each person. When we come together to share, the community appears." As stated earlier in the theoretical overview on social suffering, suffering is lived at the junction of the individual and the collective. It is shaped by social forces but varies in accordance with the variegations of individual lives. Like Emma intimates, to share does not imply sameness.

Emma's thinking finds further articulation in philosopher Jean-Luc Nancy's meditations on being-in-common and community. "Being-in-common is not common being," Nancy (1991, 29) writes in *The Inoperative Community.* For Nancy, and by analogy for Emma, to live in community is above all to share existence. Community names the enactment of relations between people through the activity of sharing. In turn, sharing unfolds through interpersonal communication, contact, participation in nearby others' lives. By emphasizing the act of sharing, the language of community does not ground the latter in an original essence (*the community isn't the disease*) or project. Nor does it treat community itself as a finished entity. Never is sharing

complete, says Nancy (1991). It is an ongoing act of contact through which singular beings touch each other.

I like the language of sharing because it postulates simultaneous separation and proximity between contacting parties. “From one singular to another, there is contiguity but not continuity. There is proximity, but only to the extent that extreme closeness emphasizes the distancing it opens up,” Nancy writes in *Being Singular Plural* (2000, 5). Community designates a relation of sharing that does not postulate interpersonal fusion. It is a relation of communication amongst a plurality of proximate but separate beings. In this manner, Nancy’s and Emma’s locating the act of sharing at the heart of community does not presume fusion into collective being. In community people do not commune (melt into a single essence) but communicate (share, contact, collide). This is not to say that separation presupposes marked differences between separated beings, but that interpersonal separation allows beings touch each other’s skin and souls (Nancy 1991; 2000). Community is thus predicated on the presence of similarities between separate beings: “One cannot make a world with simple atoms. There needs to be a clinamen [a swerve in atoms’ trajectories]. There needs to be an inclination from one toward the other” (Nancy 1991, 3). Seen thus, community is a gathering of separate beings who incline toward each other, exist close to (with) each other. Sharing qua co-presence.

I let Emma’s and Nancy’s intermingled thoughts on the centrality of sharing to community steer my train of reflection. Following their lead, the story of community unlocked takes as its starting point the commonalities of suffering between people of the sickle cell community. I think of those commonalities as an inclination bringing people in proximity. The sickle cell community burgeons and subsists through the sharing of these commonalities – communicating, placing their similar lives in common. To commingle Emma’s and Nancy’s words: the sickle cell community appears when its people come to share their contiguous, never continuous, suffering. They touch one another by virtue of their proximity afforded by their inclination to each other, their similar lives. I learned to see that sharing suffering allows people of the sickle cell community to develop a form of co-presence. A kinship, even.

The act of sharing is not the story’s resolution. Relationships forged through the sharing of suffering flower into empathic intimacies. People of the community do more than share

existence. They care for one another. Deeply. From my perspective, sharing suffering allows participants to develop ties of empathy, which take the form of mutual acts of care. As chapters communicate at turns explicitly or implicitly, small and large gestures of care move through people's interactions. It is, unexpectedly, a form of care that aims to lighten community participants' suffering. It is also one that has a strong religious cast. When steeped in Christian logics of salvation, empathic intimacies developed through sharing suffering become sinews binding together people of the community. The sickle cell community thus lives on through the twinned acts of sharing and gifting suffering. As I will try to convey, it becomes a therapeutic sanctuary wherein salvation from and through suffering may unfold. At bottom, then, this thesis authors a braided narrative of suffering and community.

authorial sundries

Thesis aesthetics adheres to an ethics of partial authorship. To the best of my ability, I pen the three substantive chapters without asserting full authorship over the matters discussed therein. I perceive my mandate as that of interpretive guide. Accordingly, I avoid as much as possible dictating truth. Perforce I put forth a singular view of the world and thereby postulate certainties. Nonetheless, I want to leave a window ajar for different interpretations to crawl in. Text belongs to reader. Alternative readings of scenes depicted can be but productive openings. In an effort to relinquish interpretive control, I tend to couch my ideas in conjectural, above argumentative, language. I share impressions, thoughts, hunches. The thesis may thus be contemplated as a manuscript of impressions over a litigation of truth inexorable. Chapters are peppered with footnotes describing the limits of my understanding and the rookie mistakes made during fieldwork – not to nullify my analysis, but to adhere to a principle of intellectual honesty. In the same spirit, I make analytical and theoretical exposition sparse, now and then. Events are narrated as people of the sickle cell community and I have lived through them, without buffing out their unfinishedness and occasional ambiguity.

These events are chronicled over three conventional chapters, converging in a concluding one. Each chapter unthreads one of the three modes of entanglement of sickle cell and the world. The opening chapter explores the inextricability of sickle cell suffering from antiblackness and blackness. The second chapter shifts perspective to sickle cell stigma. I foray into two modalities of stigma, witchcraft discourses and taboo, to recount their entanglements with illness. The

chapter also tells of the cultural affinity between the community's participants – a cultural affinity that is inextricable from blackness. The last substantive chapter rolls on to the third dimension to suffering, faith. It plumbs the depths of evangelism on account of its marked popularity in the community. Finally, the conclusion, beyond tying preceding chapters together, proceeds as an open-ended exercise in stretching possibilities of thought. Its content will disclose itself in time.

Conversations sprinkled throughout are retrieved from my field journal. I gleaned gritty details – smells, sounds, sights – principally from my journal, but supplemented with memory. Informal conversations went unrecorded. Sometimes I furiously scribbled down people's words before they scattered to the four winds. Other times I reassembled conversations retrospectively, jotting down as much as I remembered: words, sentences, tones of voice, pauses, postures. In all transparency, sometimes the task was undertaken the day after, especially if fieldwork dragged into the night.[9] The implication is that my narrative reconstructions may be skewed in minor ways. Moreover, I have translated and edited conversations to maintain intelligibility and reduce redundancy. I am careful ever to stay close to the original words. Despite such tinkering, I believe to have preserved the meaning and intensity of interactions. I ask that any unconscious or legibility-minded reality distortion be forgiven.

Three notes on style to guard against confusion. First, special descriptive attention is paid to the weather. "We're human thermometers," patients like to repeat. Humid, airless heat renders many ill – in pain. Conversely, dry heat is soothing. The cold, damp cold most of all, can trigger crises both minor and major. So can steep temperature fluctuations. Integrating atmospheric descriptions is an effort to channel my companions' meteorologically sensitive illness through the page. Second, narration is fragmented. No subtitles detain the ethnographic present within self-contained analytical sections. Instead chapters unravel in unfinished fragments separated by vacant spaces. Such narrative fragmentation, in my view, aids the text in staying open. The void separations between small scenes permit them to comment on one another in ways I might not have imagined, and

[9] I have in mind three scenes. In chapter 1: the gala dinner. In chapter 2: the moment I share with Alice in her apartment, and the picnic in the park. I filled my journal the following morning.

leave space for the reader's imagination to extend or circumvent my renditions.[10] Third, and relatedly, chapters are left unnamed, the better to preserve semantic flexibility, and to sustain narrative flow.

With this in mind, the next chapter turns to sickle cell's mingling with antiblackness and blackness. It finds anchorage in one person's story.[11] That person is Aisha: unapologetic, clear-eyed, outspoken about her community's plight, herself bearing the open wounds of history (Kincaid 2001). In the following, I juxtapose her voice with various others' in order to alternate between miniature and bird's eye views of the sickle cell community. This strategy might render intelligible circumstantial truths about the alchemies of blackness and sickle cell, and the intrusion of antiblack violence upon the sickle cell community.

[10] Three ethnographies have borne an implicit influence on my general approach to ethnographic writing: Angela Garcia's *The Pastoral Clinic,* Lisa Stevenson's *Life Beside Itself,* and Munira Khayyat's *A Landscape of War.*

[11] On terminology. The permutations Black/black, Blackness/blackness, anti-Blackness/antiblackness exist within Black/black scholarship. Some prefer the upper-case version (Bain 2024), some prefer the lower-case version (Bruce 2020), and yet others see-saw between the two (Sharpe 2016). Because Christina Sharpe is the main interpretive guide shepherding me through the topic, I use her terminology: Black, blackness, antiblackness.

Chapter One

In our culture we are angry with our history, we are angry with slavery, we hate the French. But we cannot stay angry forever.
– Yves, during a support group meeting.

Aisha is a sickle cell mom. She is fifty-three years old. Her severely sick son, now thirty-five, is still dependent on her care. He lives a two-minute car ride from her house, in an oddly quiet pod tucked within the hub of Montreal. He suffers from pain crises of relentless severity, and therefore needs his mom close by. They are one of the many mother-and-child duos I meet in the sickle cell community: her world revolves around his, and his around hers. Sickle cell entered their lives, thereby strengthening the bond between them, the moment a pain crisis first befell him. He was six months old, Aisha a single mom of eighteen. Upon learning of the pregnancy, the father abandoned the baby to Aisha's care. They were unwed, and in Niger, a Muslim West African country. They had sinned.

For many years Aisha faced motherhood braced and alone, struggling to shield her son from the reaper's sickle, in a time and place where sickle cell diagnoses were thinly-veiled death sentences. Only one pediatrician worked in her city. Her hospital suffered from chronic blood shortages, and her son escaped death by a hair's breadth twice. As a young mother with no resources, healthcare became nigh impossible to afford.

Her whole community beyond her immediate family rejected her. Pregnant girls like her were forbidden from attending school. She had to fight and fight to keep her class seat. She succeeded, but suffered her peers' relentless and spiteful bullying at school. They hurled insults and objects at her. Her community – friends and neighbours – ostracized her. When they caught wind of her son's illness, they took greater distances. Her religious community, too, alienated her. She had brought dishonor upon herself. Her son's illness was but fair retribution for sin.

Aisha and her son departed for Canada six years later. Surely, effective therapies would exist in a medically advanced country. Surely, state-of-the-art medical technologies and universal healthcare would help protect her son's life. It was not long before she understood that they do not. Not people like them, people of darker flesh, people whose spilt blood trails biomedical progress. Black people.

Because here in Canada, what she thought would be the best place in the world, a place she imagined warded against sickle cell death, she became a visible minority. She now fathomed the depths of injustices facing people who live with sickle cell, people whose suffering goes unrecognized. She learned that no cure, no sickle-cell-specific treatment had ever been developed for sickle cell. She learned that, to protect her son, she would have to take up the mantle of sickle cell advocacy. She would have to fight for him, but also for the sickle cell community. She would have to fight to effect broader change. When she imagines a world free of sickle cell suffering, she imagines a world rid of antiblack racism. In her life, the two are inextricable.

One day Aisha tells me a story. We are seated opposite each other at her small kitchen table – dark, wooden, cool to the touch, littered with laptops and bills and forms and pamphlets. Her home office, she later confirms. My back is to a large window whose gauzy blinds are mercifully drawn, but the sun breaks through, a dull sting on my red shoulders. Aisha's obsidian eyes are fixed on the cluttered mess covering the table between us, hands folded to her chest. She seems out of body, wrapped in the daze of memory, the accrued and blending aches of a human life.

"In the middle of the night I received a call. It was a girl from Alberta." Aisha mimics the shrill voice and panicked tone of the girl: "Miss Aisha, miss Aisha, I'm in the emergency room, I'm in pain, I'm in pain, it's been six hours, I haven't seen the triage nurse, I'm in pain, I'm in pain, miss Aisha I'm in pain, they are going to kill me!" Aisha then asked the girl to put her through to the nurse. She spoke to him. She asked the nurse if the hospital possessed a sickle cell protocol. The nurse replied in the affirmative. Manifestly he and his colleagues had flouted it, as sickle cell patients must be seen within thirty minutes. Their lives are on the line. Aisha fought, as she had all her life, for the girl to be taken in. The nurse resisted. At length, he gave in. The girl, in the throes of a pain crisis, was admitted.

Aisha followed up the next morning. She learned that a woman from Edmonton's sickle cell community had checked in on the hospitalized girl. At the hospital, medical staff had justified their indifference to the girl's pain by claiming she had developed narcotics addiction. They had not believed her and thought her a drug seeker: a manipulative, malingering patient addicted to opiates feigning her condition to receive pain medication.

That girl died at the hospital a few years later, in 2023.

Aisha's eyes flash with quiet rancour. "The reason I'm telling you this is because she did tell me they were going to kill her. She knew. And now she has left a four-year-old girl to her aging mom."

…

They are going to kill me! Eventually they did, says Aisha. A sickle cell advocate like Aisha, the deceased woman was vocal about the poisonous alchemies of antiblack racism and sickle cell. Leading a sickled life in a Black body translated as the disbelief of her pain on account of racial stereotypes – accusations of ill will, of drug seeking. It meant living in a state of dread, she once said. In her words: racial discrimination rendered sickle cell "dreadful." Dread of racial profiling. Dread of care denied. Dread of death at the hands of supposed ministrants: clinicians.

The young woman who died was Black. So is Aisha. So do the people of the sickle cell community identify as such. Iatrophobia (Washington 2006), or the fear of medicine induced by biomedical abuses committed against Black persons, appears to pulse through the community. "There is mistrust against healthcare in the community," Aisha tells me. "They [clinicians] are the problem, not the solution." The community's people have come to identify biomedical healers as perpetrators of racialized harm. One passage from the opening "Sickle Cell Poem" I left out similarly notes the community's "natural mistrust of those / Who are supposed to help." I hear second-hand accounts of patients resorting to African herbal medicines instead of hydrea, and failing to attend regular biomedical check-ups, owing to their frayed trust in biomedicine. While many people in the community question clinicians' benevolent intents, I do not meet anyone who admits to personal treatment non-compliance or refusal of hydrea. This said, generalized mistrust orbits hydrea. A number of people disbelieve clinicians' reassurances that its induced infertility is a temporary after-effect. "You [clinicians] save their lives and make them individuals who will be childless," Aisha hisses, with reference to hydrea. "To me, as a Black woman, it feels as if we are being failed again." Hydrea, what one hematologist I know calls a "magic treatment," is feared as an object of medical harm, a biomedical weapon wielded to render Black patients childless. Attribution of ill intent is limpid in Aisha's words. *They are the problem, not the solution.*

I learn to appreciate the centrality of iatrophobia to the community's illness during the very first of Crescent's support group meetings I join. This day, the tepid air is laden with collective

despondency. People share their sorrows, tell similarly harrowing experiences with healthcare, similar fears of its racial violence. Most stories pertain to emergency medicine. Approximately forty people are seated across the room's wide concentric circles of chairs, faces long as a fiddle. It seems all have their own stories of racial discrimination to tell and all appear to nurse similar grievances against healthcare practitioners. I sit at the far end of the room next to Cam, a patient we meet in the next chapter. I am silently observant. A notetaking wallflower.[12]

"We are Black, so when we have a crisis in the middle of the night and we are in our pajamas, we must make ourselves look pretty and respectable. Otherwise, white staff won't take us seriously," a woman says heatedly. "It's a huge stress for me. They don't care."

"Yeah, exactly," Yves – the patient we met in the introduction – replies from across the circle of chairs. "Getting dressed up, and going to the hospital to face a white nurse who doesn't care, and having to educate her about sickle cell while we are in pain…that requires a level of energy we don't have."

"Or when we are abandoned in the hallway for eight hours," a woman adds, downhearted.

After a few similar comments are voiced with alternating sourness and dejection, a woman recounts a gruelling encounter with "white paramedics," who left her alone in the ambulance for hours while seized by a crisis. Collective outrage palpably burbles in the room as she speaks.

"It's important for us to reappropriate our racial identity, to imbibe ourselves in our ethnic identity," the support group moderator says gently in response to the flurry of patient testimonies, drawing sullen nods from the crowd. She, like most people sitting in the large circle of chairs, is a first-generation immigrant. She is of Haitian origin. "I do not consider myself a Quebecer, because I am not welcome here. But we did not choose that reality," she says, "so how can we survive in that reality?" She is referring to the climate of racism entrenched in Quebec. She is not welcome, because she is a Black immigrant.

For the remainder of the afternoon, people trade strategies to cope. "To take care of each other and ourselves." To care for each other in an antiblack world that does not recognize the pain or suffering of Black persons. In North America, Black persons' pain and suffering are disavowed in clinical spaces and beyond (Bourgois & Schonberg 2010; Brand 2001; Rouse 2009; Sharpe 2016). As Carolyn Rouse writes in her clinical ethnography of healthcare

[12] Because this was my first immersion in the field, I was unskilled at efficient notetaking. That is why the testimonies to follow have meagre detail. I tried to salvage as much as I could.

disparities and sickle cell, *Uncertain Suffering,* "the Black body continues to be treated as less capable of suffering and more capable of causing suffering" (2009, 124). Their pain is chronically undertreated, because the authenticity of their suffering is questioned (Bonham 2001). They are believed to *feel* less pain, by virtue of the historical hardships their people have endured (Sharpe 2016). Sickle cell hospital admissions hinge on trust – trust of their invisible pain, pain that is inaccessible to the witness (Scarry 1985). But identification of so-called legitimate suffering is racialized, and Black patients tend to fall outside practitioners' parameters of authentic suffering (Rouse 2009). Because clinicians' assessments of pain are racially skewed, "many medical practitioners doubt that their [sickle cell] patients are in severe enough pain to require strong opioids" (Rouse 2009, 125). They label sickle cell patients as drug seekers and "block what they consider unwarranted access to powerful narcotics" (Rouse 2009, 125). Consequently, Black patients are administered inadequate palliation (Bonham 2001; Rouse 2009).

Rouse (2009) further highlights the circulation of widespread racial narratives stereotyping sickle cell patients as a culturally distinct group that is socially dysfunctional, prone to violence, poorly educated, and dependent on opioids, in hospitals. These tropes are not confined within clinical spaces. In North America, including Canada, the Black body is "culturally encoded" as "moral transgression and violence," writes Black Canadian poet Dionne Brand (2001, 36). Black literary scholar Christina Sharpe claims analogously that, while terror is visited daily upon the Black body, the latter itself becomes the "carrier of terror, terror's embodiment" (2016, 15). Black existence, she writes, means living with the terror of racial violence while being castigated as the perpetrator of terror.

Perpetuating the injurious notion that Black populations are a culturally problematic and threatening group, these narratives seep into the clinic and impact the quality of care proffered. As a consequence of the entanglement of sickle cell and broader racist narratives within the clinic, many sickle cell patients are labelled drug seekers at the hospital, perceived to be hostile and manipulative (Rouse 2009). The deceased Albertan woman is one of them. Hers is a tale of which I hear other variations throughout the summer. Cam, a patient we meet in the following chapter, has undergone a similar experience. Aisha's son, too, is frequently denied adequate opiate dosage at the hospital. That is why his mom always accompanies him. Why other sickle cell parents I know never let their children step into the

hospital in their absence. “They need someone to fight for them when they can’t speak,” says Aisha.

“It’s the healthcare community that is creating our problems,” Aisha tells me. “When the child is small, they give him the drugs. But the minute he turns eighteen, they say he’s a drug seeker. How did this shift happen? You [clinicians] created that. And who is left with those problems? Families.” She pauses, a thoughtful bitterness depicted on her face. Louder now: “As a Black woman, all of that bothers me. I question the system. The way they’re treating our kids, the way they…they don’t take care of our health. As a Black woman, I see that as a failure. How they’re just leaving the problems to the families…” she runs her fingers through her short silk-pressed hair, staring into space. “They end up hurting our kids deeply, you know.”

The tendrils of iatrogenesis, or medically induced harm, spider out beyond the hospital. Aisha compares sickle cell to other chronic diseases which, in her and many others’ views, receive greater political and medical attention: diabetes, cystic fibrosis, and hemophilia. Diseases that have their own drugs, she claims. Diseases that do not impact Black populations to the same extent as sickle cell. Along her years of advocacy, she has not witnessed much progress, as she has encountered resistance from health agencies. According to her, were the sickle cell community not Black, she and I would not be having this conversation. Sickle cell would have a magic pill.

…

Crescent’s support group meetings unfold in two parts. For the first two hours, a healthcare professional moderates group discussion. Participants stretch the conversation for another two or three hours, gathering in tight huddles to chat more intimately, all while snacking on sweet or savoury pastries Crescent’s president has baked with his daughter. I mill around during the latter part, bumbling between dispersed groupings.

One day, my awkward errancies land me in a pool of chatter coalescing near the food table. As human affairs tend to proceed, conversation flows to the rhythm of the loudest voice. At present, that would be a tall patient in her thirties. The woman’s deep, raspy voice is possessed of a strange magnetism that lures other huddle-hoppers to her radius. Little by little our little gaggle grows. Just now she is deploring the societal invisibility of, and indifference to, sickle cell. “It’s

no wonder no research gets done," she says wryly. "It's a Black-person disease." People around her nod vigorously. Her words clot into a silence thick and dark as tar. She sighs. "I'm so glad you're here, Severine." Her eyes, pools of embittered hope, find mine. "We are Black, so no one listens when we speak of our pain. You're white, so people might listen." For this reason, she has hopes of my research receiving state funding. All traces of irony have dissipated. I flounder clumsily, tongue-tied. She ignores my tactless discomfort and goes on beweeping the medical curriculum for glossing over sickle cell ("they spend fifteen minutes on it!"), before sharing her recent therapeutic experiment undergoing oxygen therapy. Hydrea, the low-grade chemotherapy prescribed to most patients, does not work well for her.

Later that same day, before bidding farewell – we never cross paths again – I broach the topic of hydrea with her once more. Originally, hydrea was developed to treat leukemia. It is used off-label for sickle cell patients, as it helps to diminish the number and intensity of pain crises. That is all the sickle cell community is left with, she tells me now. No one cares to research a disease-specific treatment for sickle cell, one which would be effective for all patients, one she thinks would have fewer side effects. The sickle cell community must make-do with a dearth of therapies (Fullwiley 2011).

I encounter pervasive feelings of race-based medical injustice all summer. While this woman implicitly compares sickle cell to leukemia, cystic fibrosis appears to provoke the strongest sentiments of racially motivated neglect. Cystic fibrosis, like sickle cell, is a recessive monogenic disorder. Cystic fibrosis, unlike sickle cell, is a mythically "white" disease. In many ways the two life-threatening genetic diseases mirror each other. In many ways but one: race.

Aisha herself is quite vocal about sickle cell's scientific neglect. "The neglect is beyond neglect," she says as we talk in her home. "The government doesn't even want to hear about sickle cell." Aisha is a well-known sickle cell advocate who labours indefatigably to insert her community's suffering into the public sphere as an issue of concern. She lobbies members of parliament, senators, and pharmaceutical companies to magnify societal attention to sickle cell. She has worked with Crescent for decades, and now devotes her activist energies to a larger sickle cell association based in Ontario. This is why we first meet in Ottawa.

In the torpids of late June, her sickle cell association organizes a symposium in Ottawa. Many in attendance are from Quebec. The annual symposium gathers patients, their parents, activists, and a few researchers in a small conference room. Its goal is to update the sickle cell

community on the state of research about sickle cell as well as activist initiatives. It also provides a space where lived experiences may be shared, like most sickle cell events. The symposium is a day-long mixture of research presentations, patient testimonies, and group discussions. Most research presented addresses health inequities facing the sickle cell community from various angles. Broadly speaking, they discuss unequal access to healthcare and costly treatments, stalling research on disease-modifying therapies and potential cures, and systemic barriers to blood donation impacting the Black community. Unanimously, they call for policy changes to confront antiblack racism and to funnel state funding into innovative research.

Aisha is at the helm of the event. From the churchy lectern at the front of the room, she gravely opens a round of patient testimonies with a minute of silence for that year's losses. A few people have passed in the sickle cell community. Each year, she takes a moment to acknowledge the "profound losses that shape the community," she tells me another day, because "the community has been forgotten for such a long time." It is her way of bringing them into the world, of recognizing that their deaths matter, of acknowledging the grief weighting the community. No one else does.

After putting an end to the minute of silence, her subdued tone swiftly switches gears. She veers to the issue of racism. Her voice rises, frank, accusing, poignant. She states that lost lives are evidence of critical gaps in healthcare equity. At the end of her speech, Aisha cites Black novelist Toni Morrison: "The function, the very serious function of racism is distraction. It keeps you from doing your work. It keeps you explaining, over and over again, your reason for being." Resounding through the mic, her breaths are quick, sharp. Charged with bitterness.

"Each time we stand up and ask for something, we are questioned. Our community doesn't face the same treatment because of the colour of our skin. We need people to listen to us. We want people who will support what we need." Her eyes swoop over the audience of about fifty sombre faces scattered across the room's ten round tables. Then she adds, "Not people who tell us what is to be done."

Because of the colour of our skin. When Aisha attests to the sickle cell community's unfair treatment, she is referring in part to funding disparities between sickle cell and similar genetic diseases. One of them is cystic fibrosis.

During an earlier sickle cell event, one of Aisha's close friends, also a sickle cell advocate, compares the funding allocated to sickle cell and cystic fibrosis. Sickle cell affects

twice as many Canadians as does cystic fibrosis, he says. Yet, in his words, it receives fifty times less state funding for research. “This disparity exists because people affected by sickle cell are Black. And the disparity translates into fewer clinical trials, fewer treatments, and ultimately, fewer lives improved and saved. More research is *crucial* to treat sickle cell more effectively. We need money invested in innovation – innovative research to work toward a definitive cure. Increasing funding is a matter of necessity.”

They are far from anecdotal, such deeply felt accusations of unfairness, in addition to being redolent of sickle cell activists’ discourses south of the border. As sociologists Wailoo and Pemberton (2006) inform us, sentiments of racial injustice related to cystic fibrosis are pronounced in sickle cell patient communities across the United States. Cystic fibrosis impacts approximately half of those with sickle cell in North America. It is widely associated with people of European descent and has come to be portrayed as sickle cell’s “white” version (Wailoo & Pemberton 2006). It also unequivocally receives greater state funding in the United States. Sickle cell impacts twice the number of cystic fibrosis patients but receives less than a third of cystic fibrosis’s federal funding (Lee et al. 2019).

In Canada, the situation is a tad opaque but appears to run parallel, save for the cystic fibrosis to sickle cell ratio. Canada’s sickle cell burden is about a third greater than cystic fibrosis’s. I have found no systematic analysis comparing funding levels. Commentators nonetheless estimate that the Canadian state invests more generously in cystic fibrosis research, albeit without providing clear numbers (Pendergrast et al. 2023). One hematologist I meet at the hospital, but never interview, does mention to me that their sickle cell unit’s grant applications are reviewed much later than those from other departments. “We always come last,” she says. “We always have to wait longer.” She does not have the chance to expand before haggard-looking interns whisk her away. Still, she hints to sickle cell’s low ranking in funding agencies’ disease hierarchy, in line with the sickle cell community’s arguments.

Appearing to enjoy greater attention from funding agencies in North America, cystic fibrosis research has been more productive than its racialized counterpart. Its patients have a wide array of treatments and medications at their disposal, not least of which their “magic pill,” trikafta. While trikafta is not a cure, sickle cell’s lack of disease-specific treatment relative to its “white”

counterpart fuels the accusations of unfair treatment running through the sickle cell community.[13]

Beyond cystic-fibrosis-related grievances, Aisha's claims that "they are just letting the community suffer in silence" are not historically unsound. Indeed, sickle cell research has a grim history. In 20th-century United States, the cradle of sickle cell science, clinicians thought race to be biological. Based on this biologized notion of race, clinicians and health scientists relied on the sickle cell gene, which was found primarily in Black populations, to demarcate "white" and "Black" racial boundaries (Tapper 1999). That the trait was occasionally discovered among "white" Americans did not prompt clinicians to reassess imagined linkages between race and genes. Instead, they questioned the so-called racial purity of white patients (Tapper 1999).

Troublingly, the epidemiology of sickle cell bolstered anti-miscegenation legislation in the fifties (Rouse 2009). Clinicians and scientists mistakenly believed that "racial hybridity" explained the presence of the sickle cell trait among non-Black populations. Terrors that "Black blood" would sully the white population's health shot through the American imaginary. Sickle cell has thus long served as a means of ascribing race. As a result, Tapper (1999) claims, sickle cell further pathologized the Black body by treating it as a source of genetic contamination. Importantly, these biologized associations between blackness and sickle cell continue to shape 21st-century public and clinical imaginaries about the disease (Wailoo & Pemberton 2006). They linger within the sickle cell community itself, as we will see.

On the warmer side of the Atlantic, sickle cell research emerged with the goal of racially delimiting ethnic groups within the larger (and fictitious) "Black race." It is in the 1940s that scientist-colonial administrators first took to investigating the trait and disease. Drawing inspiration from American sickle cell research, their goal was to document racial-cum-biological variations between African ethnic groups. To this end, they stencilled hemoglobin frequencies (disease severity) onto purported phenotypic differences between ethnic groups. Sickle cell testing was instrumentalized to catalogue ethnic heterogeneity and re-write the territorial bounds of ethnicities in biological terms (Fullwiley 2011). In this sense, Fullwiley (2011, 161) argues that the sickle cell trait became a colonial "technology of racial classification" that has lingered on. Indeed, political will for this kind of racial classificatory research has persisted until the early

[13] The severity of cystic fibrosis should not be minimized. According to Cystic Fibrosis Canada, as of 2025 median age of death is 41 years.

2000s – despite African states' financial woes (Fullwiley 2011). Meanwhile, illness was of little interest to this research. Fullwiley notes that this dominant scientific orientation to sickle cell research "may have actually precluded the possibility that sickle cell could figure as *a disease warranting care at all*" (2011, 168; italics mine). Historically, then, the health sciences have brushed aside the realities of those who live with the disease.

Whether sickle cell has acted as a biologized proxy for blackness in the United States or ethnicity in Africa, genetic medicine and science are the principal culprits for the conflation of sickle cell with blackness. And if health sciences have never neglected the genetics of sickle cell, they undeniably have discounted the suffering of those who live with it. In light of sickle cell's disturbing history, Aisha may figure right. Her people's suffering seems to have been inconsequential to bioscience. "They're just letting the community suffer in silence," she says. Researchers have feasted on their sickled lives to satiate their intellectual curiosity about human genetics, or to demarcate racial boundaries.

We're Black, so no one cares when we speak of our pain.

…

"We're not doing such a good job as a society," Aisha reflects somberly as we chat in her kitchen. "Every day we [globally] lose a thousand people from sickle cell, and the majority die before age five. Those dying babies leave families in a state of permanent grief and…and" – she appears to search for the right word – "…trauma. Because they're dying crying in pain. We should do better. We should do research. But they're just letting this community suffer in silence." Aisha lifts her pained eyes to mine. The pain hardens and her eyes narrow when she speaks next. "How would you call this? Injustice carried out through the medical system. It's the most *inhumane* form of injustice."[14]

Health agencies allocate funding to issues that are not priorities to the sickle cell community, she says with quiet frustration. Such as immunization campaigns perennially deployed across the African continent.

[14] Matin Luther King Jr's famous words – "Of all forms of inequality, injustice in health is the most shocking and inhumane" – come to mind.

"The issue isn't immunization, so don't put money on that! Put money on the important…" she trails off, shaking her head. "This is discrimination. You focus on non-important issues, you leave out the important issues, you don't want to tell us our sickle cell status, and you want to know if we are vaccinated and add to statistics that will not help us. How are those priorities set? It's because we're not at the decision table. But if we're not, you are leaving us in a state of ignorance and continue to perpetuate behaviours that hurt us."

She sits quiet awhile, pensive, rubbing her jaw.

(I wonder, *Who is this "you?"* Not me. Health agencies, likely. Yet her next words intimate she has in mind a wider set of actors: agents of colonization.)

When Aisha resumes, she speaks very, very slowly. "Now, let me tell you a reflection I have never shared publicly. The Black community…we went through slavery. And when slavery ended in Africa, we went through colonization. And to this day colonization is not over. It's under a different form. Recently in my country [Niger], we just went through a military coup, trying to be independent. Just to get rid of the colonizer, who is still there in another form of control."

Where is this headed? I think to myself, trying to connect the dots between transatlantic slavery and sickle cell.

"So, as I push my thinking, and I look…I see sickle cell as another form of control."

"Colonial control, you mean?" I ask.

"Yes." A short silence. "Let us neglect this disease that debilitates them. Let us not do research and let them die young…" Her low voice drips with pain, or does it smoulder with anger, perhaps the two emotions are one in this moment.

"Every time something has been done to the Black community that had a negative impact on our ability to prosper and thrive and live, that's how I see sickle cell. I put sickle cell at the same level as the impact that slavery and colonialism have had on the Black community.

"A specific example. Recently, when the military coup happened in my country, France forbade the exportation of hydroxyurea to it."

Her eyes flick to my face as my eyebrows shoot up of their own accord.

"Yes," she nods gravely. "Yes. You see how bad it is. People will die. And so that's when it occurred to me that the lack of research is voluntary. The lack of resources is voluntary."

A laboured breath. "And so we bury our kids and carry on."

And so they bury their kids and carry on, because the people of the sickle cell community live and die in the long and wide wake of slavery. In a memoir titled *Lose Your Mother,* literary scholar Saidiya Hartman wrestles with the unresolved afterlives of slavery. She writes:

> I, too, live in the time of slavery, by which I mean I am living in the future created by it … The past is neither inert nor given. The stories we tell about what happened then, the correspondence we discern between today and times past, and the ethical and political stakes of these stories redound in the present. If slavery feels proximate rather than remote and freedom seems increasingly elusive, this has everything to do with our own dark times. If the ghost of slavery still haunts our present, it is because we are still looking for an exit from the prison. (2007, 133)

Black lives, she alerts us, are imperiled on all shores of the Atlantic. These are the afterlives of slavery: skewed life chances, restricted access to health and education, premature death, incarceration, and impoverishment (Hartman 2007, 6). At first blush the word afterlives might be misread as gesturing to an *after*. It does not. In the words of literary scholar Kimberly Bain: "afterlife is a practice caught in time, a space caught in time, and the time is always. *The time is now*" (2024, 8; emphasis mine). Black lives are lived on the doorway of death *now*, an enduring residue of the social and physical death of the slave, Hartman (2007) and Bain (2024) say (also see James & Costa Vargas 2012; Patterson 1982). *The past is not inert.* Transatlantic slavery is alive. Lasting. Unflinching. Its enduring violence roams the modern world wearing the cloak of antiblackness, which continues to normalise Black deaths. Hartman (2007) contends that Black people's insistence on tracing their suffering to the slave trade – as does Aisha – represents an effort to illuminate the devastating effects of antiblackness in their lives.

Other Black scholars dissolve past and present with respect to transatlantic slavery. In her prescient novel *Kindred* (1979)*,* Octavia Butler's protagonist, a twentieth-century Black woman, is repetitively transported in time to the antebellum south and back to her present time. She lives past and present simultaneously, alternatingly labouring as a plantation slave in the eighteenth century amidst her ancestors, or a working-class woman in the twentieth. From my reading, Butler brings to light the layered temporality through which Black Americans live, one that twines chattel slavery with present conditions of precarity and discrimination afflicting Black persons. By this, I mean that the injurious past of slavery crawls into the present, materializing as what Christina Sharpe calls "the wake" of slavery (2016, 2).

Sharpe (2016) creates the wake as a conceptual frame for living blackness within the protracted present of slavery (*The time is now*). Worth mentioning is that her conceptual work lifts from theorist Maurice Blanchot's ruminations on the disaster. The disaster, a shadowy notion he develops by thinking through the Holocaust, is both atemporal and aspatial. It eschews representation and fathomability, cannot be reduced to an historical event confined in time and place. No unified form holds when attempting to think the disaster, because it sits outside meaning (Blanchot 1995, 41). Transatlantic slavery, Sharpe (2016) writes, is a disaster whose lived time is always, whose spatiality knows no bounds. The disaster of slavery is incompletion, nondelimitation, "there is no time or space for its accomplishment" (Blanchot 1995, 2; as quoted in Sharpe 2016).

Her concept of the wake is both extension and crystallization of Blanchot's thinking – the idiom of the "perpetual wake" crops up a few times in his book *The Writing of the Disaster* (1995, 59). Threaded into Sharpe's concept are all four meanings of the word wake. The first meaning is the disturbed flow of water trailing a ship. It symbolises the fact that contemporary Black lives are determined by transatlantic crossings of slave ships. The second meaning is consciousness (wakefulness), representing Black persons' awareness of incomplete emancipation. The third is the line of recoil of a gun, which symbolises the violence to which Black bodies are subjected daily. The fourth is vigil. It stands for both interminable grief for Black deaths (a wake; holding vigil), and Black persons' abiding vigilance, or alertness, to harm, keeping watch over each other.

When assembled, the semantic depth of the word "wake" registers the fact that Black persons live in and against the push for their deaths. That push toward death, Sharpe (2016) says, *is* the future created by slavery. In my understanding, living in the wake creates heightened attentiveness to the presence of death in Black persons' livelihoods, to the precarity of their existence, in order to ease their way into a life beyond injury. In other words, living in the wake means possessing consciousness of the continuing afterlives of slavery so as to uncover a path of escape. In this way, the wake avails its inhabitants an analytical promontory from which they can see deep into the world.

Reprising the timelessness of the wake, Black feminist scholar Nicole Charles (2023) mobilizes the figure of a palimpsest to meditate on the afterlives of slavery. A palimpsest is a parchment whose past writings have been erased only partially. New writings are inscribed onto

the still-visible inscriptions beneath, creating layer upon layer of text. For Charles (2023), slavery's muddled paths of time are akin to layers of palimpsestic writing: they verge and touch and hold and blur into each other, the wounds of history (Kincaid 2001) gaping and bleeding in the present time. Charles (2023) articulates that the palimpsestic layers of violence, trauma, and subjugation composing the afterlives of slavery can be glimpsed through Barbadians' suspiciousness of the biomedical establishment. Slavery's residues shape Barbadians' perceptions of harm wrought through biomedical technologies, such as vaccines. Suspicion arises from the injurious history of medical neglect of Black health, forced sterilizations, unconsented cadaver dissections, and abhorrent biomedical experimentation on Black bodies (see Washington 2006). Mistrust of medicine, also prevalent in the sickle cell community, represents a form of protection against medical cruelties resulting from the historical entanglements of biomedicine and colonialism. When it comes to biomedicine, slavery feels closer than freedom, for it is "a rip forever ripping apart" (Blanchot 1995, 75) Black lives. In light of slavery's palimpsestic violence, iatrophobia's residence in the sickle cell community is protective. Mistrust of healthcare, fear of emergency medicine, suspiciousness of hydrea's benign nature, and concomitant treatment non-compliance, sit amidst biomedicine's dark history.

It may be no wonder that Aisha would draw a connection between slavery and medicine, in considering the long line of her people's blood left in its wake. From my perspective, Aisha and others in the sickle cell community suffer within, and as an after-effect of, the palimpsestic wake of slavery. The events described thus far suggest that people of the sickle cell community similarly live their suffering as an extension of the naturalization of Black suffering. Like palimpsestic writing, Aisha and her community's suffering is inked on the still-visible inscriptions of slavery. Their suffering takes form within the afterlives of slavery, and seems to make sense to them with reference to the violent past/present in which they are trapped.

To this day, colonization is not over. It's under a new form, said Aisha. The perspective of the wake helps people of the sickle cell community to understand that racialized drug seeking accusations, societal indifference to the sickle cell community's Black pain and suffering, and concomitant research funding imbalances are renewed incarnations of the atemporal wake. To the people of the sickle cell community, then, finding a path out of suffering entails exiting the long wake. Because Black bodies are allowed to suffer, the sickle cell community are condemned to bury their kids and carry on, like Aisha says. The disaster of transatlantic slavery

speaks in her, in them (Blanchot 1995, 4). Possibly it speaks louder now, engulfed as we are in the racial awareness whirlwind generated by the Black Lives Matter movement. I never witness explicit analogizing of Black Lives Matter and "the fight against sickle cell," to rest on Aisha's words. Nevertheless, we should not lose sight that the sickle cell community's vehement insistence on the entanglements of antiblackness and illness embeds in our current political moment's reinvigoration of identity politics. The sickle cell community no doubt bore the weight of antiblackness prior to Black Lives Matter. Still, the latter may stimulate the sickle cell community's identity-based discourse, sharpen Aisha's attunement to antiblackness's reincarnations in sickle cell suffering.

Recall Aisha again: *You don't want to tell us our sickle cell status. The lack of research is voluntary. Let us neglect this disease that debilitates them. Let them die young.* "Them" being, of course, Black populations. "You" being, somewhat ambiguously, health agencies and colonial powers. From the position of the wake, Aisha sees sickle cell's long-standing official neglect as part of the perpetual push toward death in which Black persons live. Sickle cell patients' deaths and suffering are, as all Black deaths and suffering, sanctioned. When Aisha remarks that sickle cell is a present-day instantiation of colonization and chattel slavery – an instantiation of the wake – she tells us that neglecting sickle cell *aims* to keep Black populations "debilitated," subdued. She tells us that colonial health agencies refuse to roll out universal sickle cell screening in Africa *on purpose,* pressing them down to death. She tells us that sickle cell, this debilitating and fatal disease whose prevalence is highly concentrated among Black populations, serves the colonial apparatus. Neglecting sickle cell, letting its sufferers bury their kids, facilitates the perpetual reactivation of colonial control over sub-Saharan Africa. As Black literary scholar Kimberly Bain writes with reference to antiblackness, "domination requires continuous renewal" (2020, 240). The mundane functions of the Black body have proven "especially fertile grounds for implementing and sedimenting oppression" (Bain 2020, 240). Pressed by the living shadow of slavery, Aisha discerns the reworking of colonial, antiblack oppression through the suffering Black bodies of the sickle cell community.

They are discomforting, Aisha's and her African peers' broken ancestral linkages to the slave trade (Gyasi 2016; Hartman 2007). That they do not descend from enslaved and deported Africans appears of little import to their insistence on tracing their suffering to its haunting violence. They are, perplexingly, making an implicit claim of victimhood, despite not

experiencing the intergenerational trauma trickling down generations of African Americans (Brandt 2001; Butler 1979; Gyasi 2016; Hartman 2007). As already noted, antiblack oppression holds strong cultural sway and political traction as a larger narrative of suffering in our current moment, both within the United States and beyond. Our globalized times are ripe for identifying with, and enlisting sickle cell suffering into, the culturally powerful narrative of Black suffering hanging in the North American ether. Explanatory recourse to antiblack racism does recur more strongly among people who have lived in Canada longer. Wakefulness to antiblack racism seems to sprout with time spent on North American soil, which perhaps signals the cultural hegemony exerted by the United States' discourses of racial identity upon Canada. I can only wonder if such racial wakefulness will, with time, ignite among the youngling Canadians I know. If this cultural milieu in which blackness and Black suffering carry such social potency, intermixed with inevitable encounters with racism in the clinic, will fertilize wakefulness: if their manifold ethnic identities will, gradually, fade behind the homogenizing identity (and label) of blackness.

My analytical appeal to the contemporary clout of racialized understandings of suffering and identity is meant to contextualize the narratives circulating within the sickle cell community. Not to dismiss their truth. Antiblackness is more than a political discourse, an orienting framework against which their suffering makes sense. Its violence intrudes upon the sickle cell community's illness, irrespective of their ancestral connections to it, irrespective of the American genesis of the discourse. As Sharpe (2016) reminds us, the disaster of slavery and its foundational violence intrudes upon all contemporary Black lives, all Black suffering. As a disaster – atemporal, aspatial, amorphous – slavery is "the impossible real" (Blanchot 1995, 38). All sense of the historically possible sinks within it. Like "a circle eternally bereft of a centre" (Blanchot 1995, 2), the disaster of slavery is not restricted to the event. It knows no limit, is a limit of thought. When it comes to the immemorable disaster, victimhood is felt in brutally real ways, but it is elastic. Lacking in essence, historical or otherwise.

Eschewing linear time and space, slavery's violence appears to overflow the historical confines of victimhood. It "ruins everything" (Blanchot 1995, 1) in its impossibly real wake, muddying the boundaries of intergenerational trauma. Let's not forget Aisha's story. Upon landing in Canada, she and her son "became visible minorities," in her words. She experienced racism in a way she had not at home, in Africa. She, a Black woman, newly suffered from its violence, violence spreading to all Black lives. She entered the wake.

Juxtaposed with the racial awareness forcefield of our times, the impingement of antiblackness into all Black lives might explain why we observe the formation of this transversal of blackness converging older and newer Afro-diasporas – and the extension of victimhood to the latter. The unfathomable disaster of slavery, or the wake, is immanent in the totality of today's Black lives and deaths, Aisha's included. It "dissimulates itself" (Blanchot 1995, 6) in sickle cell suffering, Aisha impels us to realize. With her Afro-diasporic wakefulness, energized both by the contemporary sway of racialized suffering narratives and her residence in the wake, Aisha recognizes the Black sickle cell body as a ground for the perpetual renewal of transatlantic slavery's oppression. I read her appeal to the history of slavery as an affirmation that she, a Black woman, is a victim of slavery's residual violence.

It is in the climate of antiblackness that people of the sickle cell community find each other. Bear in mind that living in the wake of slavery entails holding vigil, a "vigilant attendance to the needs … of the living" (Sharpe 2016, 10). The push against death does not smother insistence on living (Sharpe 2016). In my eyes, people of the sickle cell community reach each other not despite, but through, the dimness of the wake. They find a community of people who have in common the suffering wrought by the entanglements of antiblackness and sickle cell, who insist on living, who insist on being together. I sense that the community creates a space for them to share experiences with sickle cell, yes, but more particularly to place in common their entwined experiences of sickle cell and antiblack racism. It is the only space where they may do so. The only space that assembles people who understand their entwining, who live sickle cell in the palimpsestic time of slavery. A space where the depth of their suffering is not disavowed, where their pain does not go unrecognized, where they may care for each other, listen to each other, attend vigilantly to their peers' suffering, despite their collective exclusion from the antiblack world. Despite its neglect of Black persons' pain and suffering. And by sharing their similar suffering – similar because it is lived in the antiblack world – in the only space that avows its sharing, a form of co-presence emerges.

Yes – but something else throbs in the community. Something at which my authorial pen quails, for want of analytical confidence. It is a song I cannot leave unsung, however off-key my authorial voice.

…

Sharing the suffering wrought by antiblackness within the sickle cell community seems to flourish into a "we." So with blackness. In the sickle cell community, blackness and sickle cell commingle. The mythical pairing I discussed earlier is alive in the community. It, too, seems to forge a togetherness. My arrival story opening the thesis purposefully highlights people's flummoxed reactions upon first laying eyes on me. Think again of Yves's dazed disbelief on hearing of my uncle's sickle cell, before I mentioned our non-biological kinship.

People of the sickle cell community touch one another through sharing similar experiences with antiblackness, but also through sharing blackness. To aid my contemplations, I circle back to Sharpe (2016). She impels us to reflect on blackness beyond tropes of injury, victimhood, abjection, terror, grief, death. To be in the wake, she says, "is also to recognize the ways that we are constituted through and by continued vulnerability to overwhelming force though not *only* known to ourselves and to each other *by* that force" (Sharpe 2016, 16). To inhabit blackness is a creative project. Which means blackness is, like all identities, flexible and fractalized. I read Sharpe's (2016) discussion of blackness as a broader indication of identity's continual emergence through interhuman dialogue.

Floating on these thoughts, I try to apprehend the blackness that is shared within the sickle cell community beyond the frame of antiblackness, without breaking dialogue with it. I not treat blackness, Black identity, or identity more broadly, as a fixed object, but as an intersubjective process. In accordance with the thesis's avoidance of argumentation, the exercise might be imagined as speculative above argumentative. I do not theorize about blackness. That work is not mine to undertake. I merely turn outward a few thoughts and inklings that bubble up in the course of fieldwork. I do so in spite of analytical disquietude, because the blackness I notice community participants share seems to contribute to forging intimacies between them.

At the support group meeting depicted above, many have difficulty understanding how a strange teenager would know, let alone be interested in, sickle cell. ("Very few whites are learning about it and advocating," a sickle cell mom says at another event.). So, as part of a frantic ploy to cultivate rapport, I mention my uncle's sickle cell. One middle-aged woman interrupts from across the room.

"What?" she exclaims somewhat forcefully, brows furrowing deep. Then, pointing to the skin on her bare forearm: "I thought you needed black skin to have sickle cell." Soon I learn to avoid allusion to my uncle, which excites incredulous stupefaction with little variance. Holding my tongue achieves little in the way of resolving the issue. I receive these kinds of comments and othering looks all summer. "Who is she?" a woman asks with a nod in my direction during a support group meeting. "What is she doing here?" from another man. "Why are you interested in sickle cell?" "I've never seen a white person with it." Ditto ditto. The assumption being that sickled cells do not course through my veins. My company rouses mystification even among those who know sickle cell impacts "non-Black" persons. They, too, often trace sickle cell to an original blackness, an "inherently" Black Africa.

Perhaps the most effective means of conveying this myth is through a small but noteworthy moment. It occurs during Crescent's annual fund-raising gala dinner. Each June, Crescent holds a black-tie party gathering patients, their caretakers, a few politicians with whom Crescent collaborates, and a handful of healthcare practitioners in a hospital's sickle cell treatment centre. In my estimate, this year an impressive two hundred people are in attendance, all clad in evening gowns or tuxedoes. Spread across the sprawling conference room, white-draped round tables appear purple under the dimmed lightning bathing the venue in ink-blue gloam. Pinpricks of white light twinkle across the soaring ceiling. Later that night, I learn the scattering of stars recalls those who have passed from sickle cell. (*a cul-de-sac of collective grief*)

As courses are served throughout the evening, a succession of people recite speeches and share testimonies from the low stage at the front of the room. People pay little attention to speakers. They are befuddled by food or engrossed in conversation. I am sandwiched between two of Cam's acquaintances at a table near the stage. My companions turn out to be avid conversationalists – until one patient in her mid-twenties steps onto the stage halfway through the night. She grabs the microphone and begins telling her sickle cell tale. Her slightly trembling voice lifts above the crowd. The boisterously easygoing atmosphere warps. Curious heads turn her way. All around me murmurs riffle.

The woman who sits to my left bears a nonplussed expression. "She's Caucasian," she whispers to Cam's other friend and me, wide-eyed. The middle-aged man to my right mirrors her surprise. The pair seem mummified, as if their tongues have shrivelled.

When the patient concludes her illness narrative, the man says to me privately, “She must have African ancestors, because she needs to have Black blood. You know, it’s an African disease.” His tone is pedagogically kind.

Bobbing my head faintly, I hum a hypocritical agreement. I lock a challenge behind my lips out of callow desperation to ingratiate myself with the community. That he would trace sickle cell to blackness, and blackness to Africa, does not jostle me. A copious number of people in the community do the same. Over and over I hear chanted two twin refrains: “It’s an African disease” and “We are Black,” with reference to the community. Cam himself, despite his knowledge of sickle cell genetics, fetters sickle cell to Africa: “It’s the most widespread genetic disease [in Africa]. That’s normal, Africans are the ones who have it! We keep marrying each other.” He calls sickle cell an “African disease” a few times, too. Adding to the sorrowing irony, some inadvertently replicate the “racial hybridity” theory that once reified fears of miscegenation propagating sickle cell to non-Black populations.

With reference to immigration, a sickle cell dad tells me, “Today, because of interraciality, phenotypes of people with sickle cell are very diverse. There are some white people with blue eyes who have sickle cell because it’s in the genes of their parents.”

His wife, who sits across from him, continues his thought. “My brother is of my colour [chocolate, in her words]. He married a beautiful Quebecer, so my niece is blond with blue eyes. She and my son have the same grandpa, the person who gave me the sickle cell gene. You understand?” Gently she smiles at me. “Even if she is like you, with blue eyes and blond hair, she and my son have the same grandpa.”

“They can both be carriers,” her husband clarifies in a well-meaning tone.

An essentialist stance lurks under these words. They imply that sickle cell spreads through “Black blood,” or “interraciality,” or the influx of Black immigrants. Said differently, the Black, Afro-descendent body is the implicit source of sickle cell “contamination.” This is the exact logic which reified fears of miscegenation during segregation-era United States: sickle cell marks patients as Black, and in turn sickle cell is marked as Black. In the sickle cell community, sickle cell is tied to blackness, which is ultimately rooted into the soil of a Black Africa. This is to say, an essentialized relationship between sickle cell, blackness, and Africa is alive in the community. To be fair, I encounter a

few exceptions to this. Aisha is one. She knows the sickle cell gene has no geographic connection to a Black Africa but to malaria, which is found outside Africa.

The vast majority of sickle cell community participants are first-generation immigrants hailing from West and Central Africa (Guinea Conakry, Burkina Faso, Niger, Cameroon, Senegal, Togo) or the Afro-Caribbean archipelago (Haiti mostly, but also Guadeloupe and Jamaica). The pervasive conflation of blackness, sickle cell, and Africa seems to reveal a powerful sense of having in common not merely sickle cell disease – and not only similar experiences with antiblackness – but an inherently Black, African disease. They understand themselves, others in the community, and sickle cell as being Afro-descendent, as having in common Black-cum-African blood. In the sickle cell community, people appear to share similar experiences with antiblackness as well as an Afro-descendent heritage splicing sickle cell with blackness.

Let's rewind to the chapter's opening epigraph, where Yves embeds the sickle cell community within a common historical narrative of French colonialism and slavery. He is referring to Africa. Black Africa. *Our disease, our history, we hate the French.* In the community, they share a blackness that hearkens directly, "biologically," to their collective African roots. *Our disease:* Sickle cell is theirs. It is Afro-descendent: descends from Africa, born in a Black African soil. So do they, so were they. I sense that sickle cell's "Africanness" plaits through their own African roots, their parallel histories of migration. Thus, what they place in common – share – in the community is more than a neutral sickle cell disease. More than similar experiences with antiblackness. Because their sickle cell gene is "essentially" African. What they share is also an Afro-descendent lineage that gathers under its wings an inherently Black-cum-African sickle cell. They share a suffering that is essentially Black, essentially African.

From my reading, sickle cell becomes a focal point of Black-cum-African identity, and an emblem of the community's distinctively Black suffering. While the sickle cell community's reification of the pseudo-scientific imaginary of sickle cell as a "Black disease" appears at first blush to counteract their antiblack activism, it might serve as a propulsive force. Sickle cell sufferers' "inherently" Black suffering might become a rallying cry for the community, and for potential allies in the wider Black community. *We are Black,* this phrase I hear over and over, seems to be more than a neutral statement of facts, more than a tragic rehearsal of

pseudo-scientific understandings of race. When embedded in the sickle cell community's anti-racist activism, *We are Black* might be read as an attestation that theirs are the bodies bearing the scars of history, theirs is the spilt blood, the "Black blood," the "African blood," drenching the ground upon which biomedicine has trodden, upon which the antiblack world keeps walking forth. *We are Black* securely positions sickle cell suffering under the aegis of Black suffering writ large, authenticates the community's enlistment of sickle cell suffering into the broader fight against antiblack racism. *We are Black* attests to the community's shared Black suffering, shared Black identity, and shared Afro-descendent heritage.

This Afro-descendent heritage – the bundle of blackness, sickle cell, and Africa – also includes culture. "Our culture," Yves says in the opening epigraph. Their sickle cell is inseparable from their blackness, but we will see that their blackness is equally inseparable from their culture. It turns out that this culture is one in which sickle cell is stigmatized. Yes, that is the reason I have written of the sickle cell community as the unique space where its people may discuss conjoined experiences of antiblackness and sickle cell. Sickle cell stigma seems to smother those discussions in their wider Afro-diasporic communities of belonging.

The next chapter swivels to the entanglements of illness stigma and sickle cell, because people of the community understand their suffering to be a consequence of the stigmatization of sickle cell in their culture. The chapter's aesthetics is pixelated. It skips from person to person, moment to moment. It is true, this aesthetics deflates depth and intimacy, heart and soul of anthropology. To prevent dizziness, I have left nameless many, but if we must mourn intimacy, a sweeping view offers a more comprehensive portrayal of the community. I hope to communicate its textures and vitality better than this chapter could, and to substantiate my thoughts about the centrality of sharing suffering to the community. In this way, we come to know a number of people in the next chapter: Emma and her sick daughter, a patient named Alice, Cam and his sick cousin Ade, and a patient named Elie.

A warning before we dive in, intended not to dismiss my interlocutors' epistemologies, but to pre-emptively position them in relation to anthropological literature. The anthropologically discomfiting notion of culture suffuses the next chapter, a notion anthropologists have – and it is no exaggeration to say – in droves turned their backs from. Indeed, critiques of the essentialist thinking underpinning the culture concept abound in anthropology. Malkki (1992), as well as Gupta and Ferguson (1997), remind us that interlaced with the word "culture" are assumptions of

rooted, territorialized existence. The word trinkles from the Latin *cultura,* meaning "to cultivate." Culture is, if you will, essentially of the soil. As such, Malkki (1992) says, invoking culture presumes isomorphism between a people and a place – the latter two wrapped up into one culture. As a result, the culture concept incarcerates presumably homogeneous peoples within the confines of bounded territories (Appadurai 1988). Place and people are conflated and subsequently treated as one discrete object, namely culture. Culture, following anthropological epistemology, is a myth of original and timeless homogeneity.

The reader will hear essentialism sing in my interlocutors' discourses of culture, as when the latter biologically moor sickle cell to blackness to Africa. A few people's tales are clotted with stereotypes, particularly those regarding sub-Saharan Africa. They might paint a much-criticized picture of Africa as "a place of darkness, as violent and barbaric" (Sarr 2023, 21), a pit of suffering out of time. Now and then they replicate the colonial vision of an underdeveloped, desperate morass of corruption and poverty mired in backward customs and beliefs (Mbembe 2017; Mbembe & Nuttall 2004). I trust the reader's discernment and refrain from pointing out each and every jarring assertion. No, I do not accept them uncritically. However, I shall not spurn community knowledge on the basis of epistemological dissonance between my interlocutors' theories of the world and my discipline's. The mandate, as neophyte anthropologist, is to prioritize open-ended curiosity over normative judgement.

With the aim of writing close to the field, I give precedence to the community's conceptual grammar, letting my fingers catch on its thorns. The idiom of culture is part of their discursive practices, theorizations of their suffering. I suspend anthropological critiques of culture to grasp people's ways of understanding their lives, and work with their perilous ones. In this spirit, the chapter attends closely to the cultural affinity that appears to facilitate the creation of intimacies between people of the sickle cell community. Bringing to life this strong sense of cultural affinity, itself connected to similar histories of migration and blackness, aids in contextualizing discussions of stigma. Because "it's in the culture."

Chapter Two

It's a dirty word, a bad word.
– a patient, with reference to sickle cell, when speaking about sickle cell stigma.

We hide it. We hide the disease.
– a sickle cell patient.

Summer begins to wane, and Crescent organizes a four-day sojourn into the city's encircling woodlands for patients and their families. Summer vacations are beyond many participants' financial means. The excursion is their sole respite from Montreal's suffocating heat. On this trip we stay at an outdoor recreation camp by a lake. Corralling its waters are forested hillsides that look like a fluffy green blanket by day, and loom like giant shadows by night.

Our sickle cell team, which numbers about forty, shares one large rectangular cabin a minute's walk from the camp's tiny beach. My room is on the wooden cabin's second floor gallery, which runs the length of the central hall. Furniture is sparse: two bunkbeds and a Billy bookcase occupy most available space. I bunk with Emma, her 21-year-old daughter, and another mother-and-daughter duo we meet in the third chapter. Emma carries the sickle cell trait, while her daughter has full-blown sickle cell.

Emma immigrated from Central Africa two decades ago. She has been participating in Crescent's events ever since her daughter's diagnosis – two decades ago. She is short and secures her coily curls in a woolly bun, her eyes black pearls that gleam with kindness. Her daughter inherited her kind heart but speaks and smiles little. She often appears distant, withdrawn within herself, sunken eyes, shoulders stooped. Translucent to others. Now and then I wonder if her shadowly bearing is a manifestation of pain's centripetal force, shrinking her world to her painful body, or simple brooding introversion.

Emma's daughter is taken ill on our trip's second day. Torrential rain befell us in the morning and shows no sign of abating. It is a relief no pain crisis has seized hold of any other patient, what with the overnight temperature drop. The damp coldness that clings to the air has triggered what Emma's daughter calls a "mini crisis." Emma spends the day nursing her sick daughter. I tag along.

In the evening Emma and I are closeted in our shared bedroom with her half-conscious daughter. People have already left for dinner – it is served in a communal cafeteria. Our deserted lodgings are quiet save for the sobbing heavens above. Emma's daughter dozes off on her top bunk, drowsy with pain medication. She is buried under a stack of blankets and clutches a hot water bottle tight to her chest, curled in on herself. In the overcast gloom a little nightlight throws sagging shadows on Emma's face. She is sitting at the edge of the narrow bed beneath her daughter. I sit on the hard bunk opposite her.

We talk a lot that night, Emma and I. Eventually conversation meanders to the judgment Emma experiences regularly from her family and community for having brought to life a baby with sickle cell. I am the one to broach the topic of sickle cell stigma. Emma has discussed it at a few events earlier in the summer, and I am curious to know more. In fact, in the sickle cell community this kind of marginalizing judgment directed against those who live with sickle cell, or what they call "the stigma of sickle cell," is a source of perpetual and universal complaint. Most also connect stigma to witchcraft. Whether they originate from the Caribbean or sub-Saharan Africa makes no difference. I wonder, does Emma experience witchcraft as the main ingredient of sickle cell stigma, too?

"No, not really," she answers, to my initial surprise. "In African families, culturally there is so much judgment. People say mean things to sick people and their families, like 'Oh are you sick again' or 'Oh look, that family has sickly children.' So people hide that they have the disease." A pause. Then she adds in a muted voice, carrying echoes of Aisha's words, "It's a shame. The disease, I mean."

"Did your family say these things to you?"

Her head slowly shakes up and down, eyes wide as if for emphasis. "Yes, often."

"I'm sorry," I say quietly. "Was that true only in Africa or here too?"

"It's here too." She gives an exasperated sigh. "It's in the communities here too."

We are silent a moment. Rain hisses against the squarely window.

Just then I ask, "You know Alice, right?"

She nods.

"She didn't know she had sickle cell before arriving in Montreal, and –"

Emma bursts into laughter, cutting me off. "Oh, that's not true." She laughs again at my flummoxed look. "She knew. She knew, I'm telling you. She was just hiding it."

With a little nervousness I counter: “I don’t see why she would have lied. Especially now that she’s here.”

Emma huffs one last disbelieving laugh and shakes her head at my ostensible gullibility.

…

Alice is a sickle cell patient of mellow temperament and short stature. She is twenty-five. I spend a lot of time with her all summer, both at the events Crescent organizes and outside. Friendship buds as the months roll by.

We first meet during a support group meeting in May, nine months after her arrival in Montreal. Her journey from West Africa earned her a 20,000-dollar medical debt to a Montreal hospital. It nearly cost her life. Sickling, or the deformation of red blood cells into little sickles, is caused by deoxygenation. Oxygen and heat are scant above the clouds. Sickle cell patients dread flying, as high altitude can trigger pain crises. This is what happened to Alice. Upon landing, she was rushed to the hospital and received her sickle cell diagnosis during her four-day hospitalization. She has been renting a downtown bachelor apartment with two Cameroonian sisters since, juggling part-time work as service staff at a university’s dining hall and business school – all the while struggling to keep pain crises at bay. She has not left the city since, and calls her family, who are in Africa, every day, and sometimes multiple times a day, especially her mom. Often tears are on her cheeks when reminiscing about the mother and family and home she left behind.

Alice regularly attends Crescent’s events. One afternoon the two of us wend the bustling warren of Little Italy, the sky above a bowl of boundless blue. I ask her why she attends these events unfailingly despite her busy schedule. “The community is like a family,” she says. “They feel what I feel, they understand me. That’s why I always go.” Her words echo the answers I receive when enquiring into the reasons people partake actively in the sickle cell community.

One of Crescent’s events consists of a picnic held in one of Montreal’s largest parks. It takes place on a sunny afternoon. Alice and I arranged to meet up right before. The day of, I make my way to our meeting point, rambling by sun-bathers carpeting the park’s low rolling hills, frisbees slicing through the heat, happy shouts and splashes resounding from a crowded pool. I find Alice sitting on a bench near the parking area. Two cornrow braids brush the nape of her neck. She is

speaking on the phone and seems in a particularly jovial mood, though washed with exhaustion as ever. Her eyes land on mine and she rises to her feet. She smiles and I smile and we hug without word.

We start down a gravelled path winding through the sprawling greenness. Alice casts her gaze about. Soon I gather she is in search of her sickle cell friend, whom she frequently calls "sister." At length we find the sister. Her face is alight with glee. She walks toward us with a spring in her steps, her toddler son in tow. A bubble of joy. Flinging her arms open, she embraces Alice and me, *kiss kiss* on both cheeks. She hands me her sick son's car seat – the pair travel from a nearby town every time Crescent hosts a fun event.

Our jolly crew sets about for the picnic. Alice's friend, whom I have seen a few times already, echoes feelings she confided to me previously: the uncontainable excitement she feels before these sickle cell events ("I get so excited in the morning, like I'm a kid and it's my birthday!"), her struggle finding a job, her sense of isolation since having arrived in Canada three months before, the absence of community in comparison with Africa, and her inability to make friends "here."

(A few weeks before, she admitted to feeling estranged from the dominant culture. "I feel lost," she said. Her face was sorrowful, her voice so soft I could scarcely hear. "Ever since I arrived, I haven't made friends. People…it's a cold country. The culture is individualistic. You can be dying in the middle of the road and people will pass you by. In Africa, we're not alone. We love…we love the human. That's what is missing here." Cracks in her breathy voice. "Not only is the climate cold, but the people are cold." At least she finds Africa's love for the human in the sickle cell community, she said, and a dearly missed sense of community.)

"People here are so cold. Just *so* cold," she reiterates now with uncharacteristic coolness as we scour the bustling park in search of the sickle cell family (a common term).

"That's so true," Alice replies in an equally colourless tone. "No one says 'Hi' or smiles on the street. How are we supposed to make friends if nobody talks to each other?"

By and by we catch sight of Cam's neon green tank top under a tree. Cam, who himself has sickle cell, always lends a helping hand during such activities. We pick up the pace and wave gaily at him. He does not notice us. He is busy setting up food trays, disposable cutlery, and drinks on folding tables that have been adjoined. The few early birds who already have arrived are draping plastic tablecloths on picnic tables about.

An hour passes merrily. The white sun now reigns high, bleeding the air of the preceding days' malignant humidity. I am talking casually with Alice and three other young women. We stand in a circle, kids chase each other around us, music carries from a nearby speaker, the eye-stinging smoke of charring meat rolls through the air. By summer's nadir, I have come to anticipate that Africa and Haiti will provide ample fodder for conversation. They usually do. I cannot replicate the long discussion that follows word for word, however. Alice and her compatriots share how strongly they miss their homes, their loved ones, and a sense of community that is lacking here. They worry about losing their cultural identity. "The most important is never to lose our cultural identity," says Alice's sisterly friend. "So many people arrive here and they forget it. It's bad. We can't forget where we come from." Equally concerned, all voice their agreement.

Yet they do not yearn for Africa or Haiti wholeheartedly. "In Africa we still believe sickle cell is caused by witchcraft," one of them says to me in a dry tone, rolling her eyes. Another glances my way with big eyes. She bobs her head up and down in mute confirmation.

"You know what?" Alice interjects urgently, gaze flitting between the four of us, "They thought my crises were caused by the devil. My dad once brought me to a witchdoctor to exorcise the devil out of me!" At this they laugh mirthlessly, and go on recounting similarly disturbing sickle cell tales which took place in Africa or Haiti. The meaning of witchcraft is self-evident to all, requiring no explanation.

In the sickle cell community, people appear to share a strong cultural affinity. And, while they long for their home with parallel wistfulness, they also criticize its culture in a like manner. Sharing melancholy – warring love and hate – for their homelands' culture seems to help them build kinship. They connect by placing in common their similar experiences with, and feelings toward, their home culture. Patients whose sickled lives have unfurled in different contexts, with no conception of African and Haitian "warmth" nor witchcraft, could not incline toward people of the sickle cell community as much as these women do. They would lack the cultural proximity that appears to help community participants reach one another. They would not know the shadings of their suffering.

Some hours later at the picnic – for sickle cell events are day-long affairs – I am sitting with my knees bent on a blanket, next to Cam. He is splayed on a banana-shaped inflatable chair, sedate in the soporific heat of late afternoon. A tree's leafy canopy casts a mottled circle of shade

over us, rods of butter-hued sunlight dance on our island of penumbra. I pick idly at tufts of grass with one hand and type a few fieldnotes on my phone with the other. Realizing my teenaged self-absorption, I make a stab at conversation. I toss my phone on the blanket and ask Cam why Crescent organises activities like this so frequently.

"Like what?" he pokes his head up.

"Like this," I say, gesturing to patches of people around us. "Picnics, summer camp, Christmas, sugar shack, support groups, and all."

Looking past me at the people about, he answers with no trace of hesitation, "It's because patients are our priority. The goal of these activities is to break isolation, to create a sense of belonging. Patients are isolated here. They don't have family. It's a space where they can feel understood." His gaze returns to me. After a second, "That's pretty much it. We try to create a space where they can be heard."

We casually discuss activism for a while. Then a cold hand touches my shoulder. I look up to find Alice lowering herself on the blanket next to me. Cam's partner squeezes in a minute later, and conversation floats to the ongoing *Festival Nuits d'Afrique.* A popular African artist is giving a free outdoors concert tonight, I learn.

"We're all going," Cam's partner informs Alice and me. "Are you coming?"

Alice whips her head toward me. Her face lights up.

…

Collective enthusiasm for West African pop music renders evident that its people have in common something other than sickle cell disease, something other than similar experiences with antiblackness – something that has to do with cultural intimacy. The sense of belonging Cam believes Crescent to foster does not seem to be forged from sickle cell in a straightforward manner. Nor does it spring forth purely from sharing Black being in an antiblack world. Crescent's logo, a bunch of chile peppers, makes explicit this cultural affinity.

Hot peppers are first drawn to my attention during a support group meeting in early summer. Alice is sitting to my left as we await the start of the meeting. Her head is bowed. Her fingers press against her forehead. The quiet pulse of her pain. Her migraines have refused to relent this past month. Has she been sleeping I ask, she so rarely does with the interminable boundlessness

of her pain, no but it's not sleep she says, it's the heat, or maybe hydrea, or maybe low hemoglobin, or everything, her hematologist is unsure, nothing to be done but hope for swelter to lift but swelter will not lift until summer's end but summer will not end for another three months. Don't worry, it's fine, she says, pulling her yellowed eyes to mine, unfocused eyes of the sleepless. The bleached glow of ceiling lights further accents the shadows beneath her eyes. A fugitive half-smile crosses her features. It fades instantly.

Alone or in small groups, other people stream in. The ascending flight of stairs leading to Crescent's office is so steep, their breaths are heaving. They greet acquaintances with beaming smiles and hug friends, then take seats in the wide circle of chairs. Today, a psychotherapist of about thirty with long braids cascading to the small of her back will lead group discussion. She is setting up the projector screen at the front of the room as Alice and I talk in low voices. Small bubbles of chatter form around us, giving rise to a polyphonous cadence of French, Haitian creole, and African languages I have difficulty parsing. The din of voices grows louder with each passing minute until it swallows the roar of cars whizzing down the street below.

After ten minutes, the class-sized room brims with about thirty people. Latecomers continue to trickle in. Crescent's president clanks in with a hemp string of blown glass chile peppers. Conversations eddy, heads turn, the room lapses into silence. A charismatic and well-respected figure in the sickle cell community, his presence commands immediate attention. He strides to the front of the room next the psychotherapist, before giving a warm welcome to the sea of jolly faces. Then he holds out the tinkling pepper vine.

"What are these?" he asks.

"Peppers," an unsynchronized choir of voices intones.

He lets that hang for a second, eyes roving over us.

"But what are they also?" he presses, evidently expecting more.

"Sickle cells." The room echoes with the words.

"Yes, they're sickle cells," he says. "They look like the distortion of red blood cells. But they're also peppers. In the culture, in the community, we know, we are tropical.[15] We eat spicy. It hurts when we eat peppers!" He laughs and people laugh and the bloodred peppers jingle. Then his smile dies, his voice drops. "And sickle cell hurts. So why speak of a banana? Sickle

[15] At a later support group meeting, Crescent's president utters the following permutation of this sentence: "African and Caribbean people, we are tropical."

cell disease, *c'est piquant*.[16] It hurts. It's not sweet like bananas." He turns his attention to two new faces, a mother and her teenage daughter. "That's the symbol of our association and the disease."

They all know, I observe in silence as the president distributes thermometers around the room while reminding everyone of biomedicine's ongoing progress, speaking about upcoming therapies. All are familiar with the alternative story told about sickling, or the transformation of red blood cells into little sickles. A banana is the image clinicians use to explicate sickling to patients. The sickle cell community has rescripted the clinical narrative, swapping the banana for the manifestly better suited hot pepper. I find red peppers on the thermometers provided by Crescent, etched on the umbrellas gifted at the gala dinner, Crescent's educational pamphlets, website, bean heating pads, clothing, stickers, pins, pens, notebooks, and other trinkets.

Sydney Mintz writes in *Tasting Food, Tasting Freedom* (1996) that food and eating represent emotionally charged symbols of belonging. "The use of food as a cultural practice is revealed as the means of expression of powerful emotions" (1996, 69). On another occasion, Crescent's president in fact calls chile peppers "a powerful symbol for sickle cell." Because of their essential nature, Mintz continues, "food and eating are repetitively constitutive of one's culturally specific humanity" (ibid.). The ubiquity of hot peppers in the sickle cell community may offer a clue as to the sense of belonging percolating it. Articulating the pain of sickle cell through a collective familiarity with spice use and invocation of their "tropical" home, Crescent's president implicitly draws on similar food practices and histories of migration. That Crescent would use peppers as an emblem of both the association and sickle cell testifies to sickle cell community participants' similar histories of migration from their "tropical" homelands – as well as their lingering attachments. The symbolic power of chile pepper appears to stem from a collective sense of cultural belonging.[17]

As the psychotherapist introduces herself during the same support group, I think of two patients, both with roots in the Mediterranean region, whose faces are never seen in the sickle cell community. "Come, just this once," I told one of them the week before. "Maybe, I don't

[16] I leave untranslated this short phrase because translating "*piquant*" to "spicy" would have betrayed the full meaning of the French word. Piquant is employed with reference to spicy food – hence the hot peppers – but it more expansively alludes to the painful sensation of being pricked or stung (as in "*piqûre*").
[17] An interesting aside: black pepper is part of the West African herbal medicine arsenal used to palliate the pain of sickling (Amed et al. 2011). I never hear anyone in the sickle cell community mention that, though.

know," she answered with incapacitated enthusiasm. I enquired into the reason they did not participate in the sickle cell community actively. Both answered with noncommittal vagueness.[18] I cannot avoid wondering if they would feel the sense of belonging fostered in the community. Are they the patients Cam had in mind when he spoke of patients being isolated here? Would they feel included and partake in the community's sharing of a "tropical" culture? Would they find their bearings during discussions revolving around culture, witchcraft, or Africa? Hearkening back to the previous chapter, would they share an Afro-descendent sickle cell, this mythical genetic heritage born in the soil of a Black Africa? Crucially, would they know sickle cell stigma?

…

Stigma is everywhere.

The feelings of people in the sickle cell community towards their homes are bittersweet, melancholic. They yearn for what has been lost irrevocably. They feel alienated from their adoptive land's culture, cold, barren, emptied of African and Caribbean warmth. At the same time, ambivalence interlaces with their attachments to their heartlands. The pull their homes exert upon them plays tug of war with the push of stigma. Crescent's support group creates a space where they may give voice to collective grievances against their culture, whose entanglements with sickle cell become a source of suffering.

One day, at the tail end of a support group meeting, I join a group of women who are trading stories of stigmatization they have experienced in Africa. They are sitting in a small straggling circle of chairs at the back of the room, near the windows. I drag a chair and settle next to Emma's daughter, who gives me a small smile. She listens in mutely, as she is wont to do.

The exchange takes place early during fieldwork. I have difficulty following along, lacking prerequisite cultural fluency. I still pick up that these women have been ostracized deeply at home for being sick or, in the case of mothers, for bearing sick children. Conversation is heated.

[18] Their homologous reticence, or inability, to offer clear answers represents a silence demanding, by virtue of existence alone, closer scrutiny. Like Ari Gandsman (2013) remarks, those silences we stumble upon in the field are more than research limitations. We should hold space for them in our thinking and writing, as they may be transformed into objects of enquiry in their own right. An analytical exercise of the sort sits at the outer edge of this thesis's scope, hence why I cannot undertake it at present. I leave this as a "food for thought" matter, which the reader and I shall mull over.

"It's really, really taboo. People don't always know what sickle cell is, so they place blame only on women for transmitting it," one mother says to me after I asked what she had meant by the "mysticism of sickle cell in African culture."

She clucks her tongue in disapproval. "It's directly linked to beliefs in witchcraft in our culture."

Alice and Emma, who sit opposite me, nod their heads in unison.

Because sickle cell is "highly stigmatized," she says sourly, women whose sickle cell status is known openly cannot get married in Africa. "No one will propose." She then recounts that her husband has come close to serving her the divorce papers, because she has given birth to a son with sickle cell. "He blamed me for the disease," she says. Crescent's president had to spend three hours with her husband to convince him not to ask for divorce. Even so, she fears he might.

Witchcraft is only one part of the stigma story. Eyes on me, Alice says, "in our culture, the family of the man will be the first to oppose marriage. They will tell him he will lose all his money in hospital bills, that he will always be at the hospital, and that he will be judged and everything."

Emma hums in agreement. My gaze shifts to her burdened face. She then looks at me and repeats gravely, "yes."

Alice launches into a description of the bullying she has endured her whole life from people in Africa and the diaspora because of physical complications related to the disease. "People always judge me or tease me or comment on my physical appearance. 'Why are you so short?' 'Why do you look like you're five?' 'Why are you so pale?' 'Why do your legs look so weird?'" She lowers her eyes. "All the time. I'm tired." Due to low hemoglobin count, an uncanny paleness may tinge sickle cell patients' complexion. They also tend to have shorter stature than average (Collett-Solberg et al. 2007), as well as jaundice (Tusuubira et al. 2019). Children and adolescents face particularly high levels of stigmatization on account of those physical markers of difference (Buser et al. 2021; Tusuubira et al. 2019). Yves, who is originally from West Africa but grew up in France, had recourse to growth hormones during adolescence. When Alice catches wind of this possibility, she immediately requests an endocrinology reference from her hematologist, hoping to lessen her home and diasporic communities' stigmatizing reactions to sickle cell.

Listening to Alice speak, Emma shakes her head in perceptible frustration. She places an affectionate hand on Alice's shoulder. Emma understands. She has suffered similar experiences of community ostracization, she tells me later.

People recount comparable experiences of culture-related stigmatization at the events I attend throughout the summer. They are typically women.[19] Across the board, stigma is understood to be an inherent component of the culture in which the sickle cell community is (uneasily) nested. Many associate stigma with the pervasiveness of witchcraft discourses and practices in Africa and Haiti. To those in the community, women in particular, stigma plays out through their exclusion from kinship networks or communities.

The stigmatization of sickle cell in sub-Saharan and Caribbean societies has been commented upon frequently in the public health literature. Resounding with these women's perspectives, the topic of witchcraft surfaces in a great deal of public health investigations about sickle cell stigma in the Caribbean (Benoit 2004; Brown 2011; Damus 2022) and, to a greater extent, sub-Saharan Africa (Anie 2024; Marsh et al. 2011; Nwezi 2001; Ola et al. 2013; Oni 2007). Most respondents present similar perspectives to those of my interlocutors. That is, sickle cell families are targets of rumors and suffer social exclusion from community events, support systems, and employment. Patients are labeled as cursed or sinful. Families rupture (Buser et al. 2021; Uyoga 2024). School children face their peers' rejection. Some avoid school entirely (Tusuubira et al. 2019). Like I am told, in the sub-Saharan region, sickle cell can be viewed as a supernatural ailment. A witch's curse. A spiritual punishment for breaking taboos. Evil spirit possession. Many do not know of sickle cell's genetic basis and believe it to be transmitted through touch (Tusuubira et al. 2018; Tusuubira et al. 2019). As Alice and her sickle cell fellows say, mothers are especially vulnerable to blame accusations for transmission of sickle cell, though gendered blame concerns hereditary diseases more broadly (Anie 2024; Marsh et al. 2011). Consequently, mothers and women patients face high risks of divorce, jeopardizing their livelihoods (Luboya et al. 2014). Importantly, high levels of stigmatization lead not only to social ostracization, but also to poor health outcomes. Since diagnoses are not always known or

[19] In my estimate, the sickle cell community is about seventy percent female. This skewed gender distribution might have to do with the gendering of care. One woman says at during an event: "Black women are weight-bearers. We carry the weight of our families and children." It bears wondering whether gendered stigma could be a contributing factor, too.

openly divulged, patients receive inadequate care, if any. As a result, survival is hampered – that of children in particular (Anie 2024; Uyoga 2024).

This cursory survey generates an oversimplified sketch of sickle cell stigma. For one, the stigmatization of sickle cell is heterogeneous and operates slightly differently across regions (Anie 2024; Munung et al. 2024). More deplorably, scholarly explorations of this stigma afford scant nuance, depth, or detail. Extant literature makes note of stigma's existence and pervasiveness but provides little ethnographic granularity. To my knowledge, no ethnographic immersion into the matter has been conducted. It seems sickle cell stigma has yet to be pieced together.[20] Despite the cloudiness, there is no doubt that the stigmatization of sickle cell is a major impediment to healthcare in sub-Saharan Africa and the Caribbean. A source of suffering.

Testimonies from people in the sickle cell community find lodging within this scholarly firmament. They are discounted from social relations like marriage and friendship, shunned from families, or suffer spurning judgment from their communities. In this sense, sickle cell can be understood an undesirable difference that defiles the humanity of those who live with it (Goffman 1963). Stigma, Goffman (1963, 5) writes, is an "attribute that is deeply discrediting." He stresses that stigma refers not to discrediting attributes, in this case sickle cell, but to social relationships which construct certain forms of difference as threats. Stigma thus refers to drawn boundaries between desirable and undesirable, healthy and sick (Goffman 1963; Scheper-Hughes 1992). It augurs expulsion from collective life.

The vocabulary of stigma brings attention to the varieties of discrimination and marginalization imposed upon differentiated individuals or groups. Note that stigma tends to map onto, and thereby reify, existing social inequalities. Those who bear the brunt of stigmatization are the most marginalized or vulnerable groups, including poor or single women (Das 2001; Bond, Chase, & Aggleton 2002). Stigma relegates them further into the margins they already inhabit. To borrow Scheper-Hughes's poignant words, stigma condemns the stigmatized to "a living death on the margins of human interaction" (1992, 374). In the case of sickle cell, living death verges on euphemism. Severe pain crises are fatal when untreated. Even if patients survive, every crisis diminishes life expectancy through cumulative organ damage. So not only does stigma consign the stigmatized to the fringes of their communities, but it carries serious implications for the health and lives of people with sickle cell. When women like Alice are

[20] Yet another silence makes itself heard.

unable to find a spouse because of known sickle cell status, or when they are made vulnerable to divorce, or shunned from their communities as a result of witchcraft accusations, women's livelihoods are on the line. When access to healthcare is restricted because large swaths of affected populations are reluctant to test for the disease, to acknowledge patients' sickle cell diagnosis, or to seek out medical care for fear of publicizing the illness, patients' pain runs at full throttle, endangering their lives. This is the gruesome fate that would meet Cam during childhood.

…

Cam is popular in the sickle cell community. He is a charismatic, witty fellow ever brimful of energy. He takes emphatic interest in my research, so I often elicit his insights when in search of clarification. His answers are always generous and thoughtful. When it comes to witchcraft – an integral component of sickle cell stigma, as is the consensus – his perspectives find consonance with those of others, including Alice and Emma.

Cam lived in West Africa until age nineteen. Like many in the sickle cell community, he deplores what he calls by turns the "culture" or "traditional customs" of witchcraft permeating African life. He does not mince his words. "All of Africa is the same. Whether you go to the Congo, Rwanda, or South Africa doesn't matter. Sadly it's the same beliefs, the same interpretations," he says, sounding exasperated. I am grateful for his deep voice – the mall's booming cacophony would have drowned a mellower lilt. A mishmash of voices, tinny pop music, and the splish-splash of an indoor fountain bounces off the domed ceiling.

Before Cam's dad passed away, he refused to acknowledge his son's disease. As a child, Cam suffered crisis upon crisis. His dad would bring him to the hospital only once in a blue moon. Cam was left to wither in excruciating, life-threatening pain. His harrowing tale is not unfamiliar. I hear a few variations of it over the summer.

"Do you know why he refused to accept your disease?" I ask Cam as he bites into his pita wrap, smearing white sauce on his lips. (*Should I tell him?*)

With his mouth full, he says, "He was very educated – a diplomat – so it's not limited to him. *All* African men…" he shakes his head and huffs a sharp garlicy exhale. "The reason they deny the disease is because it is culturally diagnosed as witchcraft. That's why women are

unfortunately the victims when they have kids with drepanocytosis." He veers on a long tangent then, displaying remarkable knowledge of genetic science. At last he doubles back to my question. He gives me an intense look and says: "You shouldn't forget that, because there is no treatment, kids die before age two, or maybe five. Just imagine. Over the generations, as they see kids die and die, people come to learn in a cultural way that it's witchcraft. If they don't know both parents carry the gene, they will blame the woman."

One might have already noticed homogenizing tendencies undergirding discussions about witchcraft and culture in the sickle cell community. I do not dismiss the truth of their accounts of witchcraft. This noted, I must insert a word of caution. African and Haitian witchcraft represents a protean, flexible complex of discourses and practices relating to supernatural powers and immoral behaviour (Ashforth 2009; Comaroff & Comaroff 1993; 1999). Though it is found across sub-Saharan Africa and the Black Caribbean, and lingers on in their diasporas, witchcraft beliefs and practices are not homogeneous (Sanders 2003). They are also tightly bound up with the legacies of colonialism. As the Comaroffs (1993; 1999) inform us, ideas of witchcraft represent the distillation of large-scale social processes, not least of which the failures of Western-driven modernization. The occult is situated within the project of modernity and offers a commentary on its immoralities and dysfunctions. Uncoincidentally, witchcraft accusations often pertain to unequal accumulation of wealth and political power under capitalistic economies (Comaroff & Comaroff 1993; 1999).[21]

When it comes to illness, witchcraft speculation is likewise tied to the intrusion of biomedicine, also associated with the occult malevolence of political and economic elites (Fairhead 2016). Beyond this historically informed association, biomedical discourses around disease can ramp up stigmatization and witchcraft speculation (Dahl 2012; Niehaus 2007). This is because their discourses around terminal illness fuel one fear integral to witchcraft and its concomitant stigma: death. I do not mean to imply colonialism begets witchcraft beliefs around sickle cell. I have too little information on the matter. Rather, I am trying to communicate that the culture to which the people of the sickle cell community trace witchcraft, and by analogy their suffering, carries sediments of ongoing colonial history. While linkages might be traced between colonialism and stigma, we should remember that people of the sickle cell community

[21] That my interlocutors would articulate witchcraft – and their culture more broadly – in homogeneous terms is itself intriguing, as it runs counter to anthropological insistence on contingency and local complexities.

understand stigma to be immanent to their African and Afro-Caribbean culture. They, like Cam, view this "warm" culture as a self-contained entity distinct from the West's "cold" culture.

As Cam's early life spools out around us, I struggle to understand paternal denial. I have heard similar stories, including some in which husbands eschew blame for children's illness by accusing their wives of infidelity. I ask again in hopes of elucidating the mystery.

"Because it's a shame," he answers promptly around mouthfuls. "You tell others that it's the second child you lose because he has drepanocytosis [sickle cell], and automatically they think you've married a witch. Who wants to live with that?" He pauses. His keen eyes are locked on mine. "In Africa, as a man, you want your family to have a good image. You don't want to be labelled as a witch's husband." He goes silent for a beat again, scrunching his greasy pita wrapper. "You know, many women are abandoned by their husbands or are downright repudiated by their families. And the fathers who might accept the disease, they often have to take their distance from their families." He shrugs. "That's the damage of culture – no, I'm sorry, but it's stupidity. Stupidity." He shakes his head sharply once more.

A witch is thought to possess an evil soul and to bear misfortune, according to Cam. When pregnant, she transmits dark energies to her baby because she does not want him to be born. "So she curses him," Cam says. People believe that "she kills the baby because she doesn't want him." And these beliefs are found in African diasporas here too, he says. "They come with it. They come with it! They leave their country, and instead of the science they are given – well no! – they can't part with their mentalities."

Like others in the sickle cell community, Cam tells me that he longs for the warmth of Africa. But, like others, he yearns for his home's culture with marked ambivalence. While people of the sickle cell community yearn for their lost culture, they also identify the same culture as a source of suffering. Especially women, but not exclusively. In their experiences, this culture they love is the wellspring of sickle cell stigma, of suffering. "I know what it is like to suffer," Cam says. In childhood he suffered innumerable crises with no palliation. Not because of an inadequate availability of pain medication, but because of his father's refusal to seek healthcare for fear of witchcraft accusations. "I know what it is to sleep two hours per night because I have spent eighteen crying."

It is no accident that Cam would title his ongoing film project *Suffering in Silence.* He tells me that it aims to lift sickle cell suffering out of obscurity, to give voice to the community's

suffering. One of his chief goals is to help rinse out stigma from his culture, as the pressure of stigma has smothered and crushed his cries for help. *It's a dirty word, a bad word,* reads the opening epigraph, with reference to sickle cell stigma. Sickle cell is a dirty word, a bad word. Not to be spoken.

…

Witchcraft is not the unique component of sickle cell stigma silencing the community's suffering. There lurks another taboo, an unwritten proscription against expressing suffering. One over which mystery rules. At a support group meeting taking place in high summer, conversation revolves around this taboo attached to illness in their culture. This meeting in particular strikes me as a venting session wherein people take turns criticizing this culture with unabashed bluntness. Air conditioning is whirring, but collective energy foams, driving up room temperature. In contrast to other support group meetings when everyone sat in a large circle, people are on their feet now. Shared frustration brews.

One patient with waist-length braids repeats a common refrain I have been hearing over and over. "Sickle cell is so taboo in our culture," she says. "In our families, there's the feeling that you don't have the right to feel your emotions. You're always dismissed, so you don't speak up. We are Black." She pauses as if for effect. "And if we are women, we don't have the *time* nor the *right* to speak. Our families rely on us. So we have to bury everything down all the time. When we are in pain, we have to stay silent." I read a blend of despair and bitterness in her voice. She has "suffered in silence" and been "isolated" before finding the sickle cell community, she says, because she cannot talk about her disease "in her [Haitian] community." With her deep, raspy voice she goes on, "We have to put on a mask of invincibility because we're simply not allowed to speak up. I'm not even comfortable crying in front of my own daughter!"

A woman next to me mutters, "yeah." Raising a finger, she says in a frustrated tone, "in our culture, when we cry they say, 'Oh, you want to cry? I'll give you a reason to cry.'"

The entire room voices their agreement. Claps blend with *Amens*.

Quick as a whip, Cam retorts through the applause, "That's true. It's been like that for generations. But why should we assume this silence? Why should we abide by this culture? If we want to go forward, we have to deconstruct these beliefs. Why take on the mistakes of others?"

Another eruption of *Amens*. One small voice resounds above the din, "But it's in our culture." She sounds disheartened, possibly implying that the immensity of issues at hand overwhelms their capacity to tackle them.

Another patient jumps in. "What if bullying happens within families? In our culture, we have the problem of toxic families." He is referring to the fear of being dismissed for speaking up about pain and illness.

A woman, whom I believe is a sickle cell mom, adds through giggles, "I learned to call this 'friendly bullying.'" Chuckles fill the air. People seem to agree with the term.

"But these comments and dismissals add up and take their toll over time," a patient my age says.

Then Yves, patient and indomitable optimist, breaks in. Suddenly all attention is on him. "That's true," he says. "There's a lot of violence in our culture in terms of social relations. So we talk about sickle cell even less. I've definitely had a difficult family…" (A young man who stands next to him snorts and interrupts, "like the rest of us.") Yves continues, "Instead of one day becoming like our parents, we should accept that we are vulnerable. We have to cut this intergenerational cycle of dismissal and shame."

Meanwhile I am scribbling in my notebook furiously. But catching words in flight is tricky. A few words and sentences flee. That is why the flow of the conversation rendered here is slightly jumpy.

"It's just taboo," a man repeats. "We are told to be strong, especially as men, and so we don't talk about the disease because we fear being judged or dismissed."

"Generations are like layers of an onion," ponders a woman. "It will take time to peel off what we've inherited." (She does moonlight as a poet.)

Conversation proceeds in this manner, circling this cultural taboo, for another hour. In truth, support group discussions never stray far from participants' sense of a collective culture. As the previous chapter's conclusion hints toward, their culture also overlays their shared blackness. *African and Caribbean people, we are tropical,* Crescent's president said. *Sickle cell is so taboo in our culture,* said one woman at the support group meeting, followed by: *We are Black.* Like their illness, like their blackness, the culture they place in common in the community is Afro-descendent. Gathered under its canopy are Black Africa and the Black Caribbean. Cultural affinity is, in this sense, inextricable from blackness. "We are

tropical" and "We are Black" are metonymic phrases. One stands for the other. Both are subsumed under the same culture. Thus, while the preceding chapter has discussed the sickle cell community's subscription to an overarching narrative of Black suffering, their Black identity seems to take shape in close dialogue with their shared cultural horizon of recent migration. The current racial awareness forcefield might render articulations of Black identity more assertive, but the latter's distinctiveness does not vanish in the North American melting pot. No: *tropical* is their blackness; *tropical* are their sickled cells; *tropical* is their culture.

If I have spilt some ink on the cultural affinity pulling people of the sickle cell community closer, it is because sharing suffering seems to hinge on their cultural – tropical, racial – proximity. They reckon that their suffering is a consequence of stigma, and in turn understand stigma as an integral part of the "tropical" culture in which they live. There are strong cultural-qua-racial similitudes between their sickled lives, which appear to enable deeper touching. Toward the end of open discussion during the same support group meeting, a man reasserts the importance of "coming to these kinds of events," precisely so they may "find similitudes" between themselves and alleviate the "loneliness that accompanies sickle cell." I cannot shake the strong impression of a therapeutic dimension to testimony, or the sharing of personal stories, in the sickle cell community.

"Today I return home nourished by everyone's testimonies," says Yves after thanking his peers for having shared (his term) their experiences. People of the community suffer from intersecting modes of social exclusion in a like manner, namely cultural estrangement in a cold land, antiblackness, and stigma. Within this community of wounded storytellers (Frank 1995), they may narrate and find compassionate witnesses to their common suffering. In sharing experiences that go unheard outside this community of suffering compatriots, in finding companionship and resonance in their suffering, a layer of this same suffering is shed. Indeed, during a different support group meeting, the moderator emphasizes the necessity of finding a strong support network and making connections with "people who understand us."

"The goal is to avoid staying alone," she continues. "There is pain, and there is this other layer on top of it that is called suffering. Having a support network can remove that layer."

"That's precisely the mission of our association – helping people make contact with others who live with sickle cell," interjects Crescent's president.

In *The Wounded Storyteller* (1995), Arthur Frank remarks that illness presents the sufferer with a truth that "must be told" (Frank 1995, 121), even if society suppresses or disavows it. Sharing this essential truth, this illness narrative, opens a window onto listening others that implicates them in the teller's suffering. It is an act that places ill persons in relationship with one another. Aligns their stories. He writes that storytelling is a means through which the sufferer both "offers [their] own pain and receives the reassurance that others recognize what afflicts [them]" (Frank 1995, 36).[22] The act of sharing suffering, understood in the sense of communicating (through testimony), is the marrow of the sickle cell community. Nancy (2007) writes that to listen is not only an act of hearing (*écouter*), but of understanding (*entendre*). As he tells us, to listen constitutes an outward opening, a responsive stretching of self, an exposure to and resonance with the world. I understand him to mean listening is a form of co-presence, with the world and its beings. It is integral to communication and, in my understanding, to sharing. To share presupposes not communion but communication, a colliding with other singular beings that sparks connections.

By encouraging people to share their truths that must be told, I sense that the sickle cell community gives rise to an intersubjective opening onto, and solidarity between, its participants. A togetherness. The community permits co-presence, or the possibility of resonance between sickle cell sufferers, in a world that disavows their suffering. Frank tells us, too, that placing suffering within "a community of pain" (1995, 37) cultivates empathic relations between fellow sufferers. Remember Tarah's words from the introduction: "It's a community that understands me." I come to appreciate that, by sharing suffering with one another, people of the community forge empathic ties of intimacy. They hear (*écoutent*) each other, listen (*entendent*) to each other, understand each other. They feel their peers' suffering like it is theirs, Alice thinks.

Given that their suffering takes form at the crossroads of intersecting axes of social exclusion, the development of empathic, deeply felt interpersonal relations alone becomes therapeutic. Co-presence heals those parts of suffering wrought by the entanglements of sickle cell with the social world. The sickle cell community is an enclave of "African" or "Haitian" warmth tucked within the cold cultural world of Canada, one where they may also find shelter from the cultural taboo leaving their suffering unspoken in their own culture. Simply being

[22] Frank employs pain and suffering interchangeably in his book. I refer to suffering.

together is healing. It remedies the lack of togetherness afflicting sickle cell sufferers beyond the community, where sickle cell stigma and antiblackness are endemic.

The support group meeting depicted above introduces a new dimension to sickle cell stigma. The taboo invoked does not seem to refer to witchcraft, but to a wider cultural norm of silence attached to illness, which regulates the expression of suffering. I have been intrigued by this for a while now. I solicit the help of a middle-aged patient at the end of this same gathering. Her name is Elie. We have spoken quite a bit through summer. The contrast of her golden hair and dark complexion ensnares the eye. Accompanied by a sarcastic wit, her magnetic aureole never fails to draw me close. Not unexpectedly I wind up by her side.

The two of us lounge on our chairs by the back windows, shoulder to shoulder. Today Crescent's president has brought an assortment of cod and beef Haitian patties, and the air intermingles with the buttery scent of puff pastry. Our eyes are glued to the toddlers chasing one another at breakneck speed under the tables arranged, as usual, in a large rectangle.

"It must be so weird for you to be here." Her remark sounds rhetorical more than interrogative. I laugh without sound, turning my head to her. She is grinning with her eyes still fixed on the hurtling children.

I affect virtuous innocence. "No, not really."

At which she shoots me a funny side-eye.

I reconsider. "I mean a little."

I laugh and she laughs louder. "But only because there are things I don't understand. I don't know anything about African or Haitian families. You all keep talking about your culture but I know nothing about it. What's this taboo around disease?"

She thinks for a second, takes a deep breath. "It's because we're not allowed to talk about disease. Or negative things. In my culture, everything has to be positive all the time. We don't talk about death, we don't talk about disease – the world is beautiful, everything is about appearances. And when we talk about pain or disease, we're dismissed. In Haiti we're labeled as the sick or fragile kid, and so we don't talk about it." A consequence of this taboo, which is pervasive in Black families (her phrase), is that friends and family avoid visiting her when she is hospitalized during pain crises every two months. And, like Cam, her dad has never accepted her sickle cell diagnosis. "He has always stayed far from my disease." I ask her why. She provides no clear answer.

Another day I seek clarification about this mysterious taboo again, as I sip iced tea with two sickle cell parents. The sun is wrathful this afternoon and the sugary drinks freeze our brains. As the mom decries low opioid dosages administered to sickle cell patients, she mentions that one barrier to proper care is that patients have learned not to communicate their pain. "In our culture you can never scream. You can't express your pain," she says, swirling her pinkish tea with her straw.

"What do you mean?" I ask.

"If you come from this community, you can never show pain, especially as a young man. Culturally, you're not allowed to show pain."

Unsatisfied, I press: "Why not?"

She appears uncertain, keeps twirling her straw. "Well…you just never talk about your problems. You hide that you have sickle cell because it's shameful. There's just a level of stigmatization."

This sort of elusive answer to my queries about stigma is representative of my time in the field. Lacking clarity on the matter, I do not risk incautious hypotheses as to the exact operations of stigma in the culture. I enquire about the stigmatization of sickle cell many times. I receive vague, if not patently evasive, answers. The short moment with Emma at the beginning of this chapter illustrates my investigative difficulties. She beats around the bush. Briskly shifts the topic of conversation. However voluble her tongue when it comes to other dimensions of illness, her guard comes up when I prod about stigma. As she also conveys, the possibility remains that people may tweak details of their stories or divulge partial truths to each other and to me. Maybe Alice has indeed buried the secret of her sickle cell diagnosis before arriving in Canada, out of shame, out of fear. Or maybe she had no secret to keep, in the absence of diagnosis. I do not know. Thus I am analytically marooned on an island of ignorance, rounded by a surging ocean of unknowns about sickle cell stigma. Further complexifying the task of teasing out this dimension of suffering, the volume of ethnographic (nuanced, granular) enquiries into the stigma of sickle cell are, to my knowledge, woefully slim.

Despite abundant uncertainties, it is undeniable that people of the sickle cell community similarly suffer from the entanglements of illness stigma and sickle cell. Swallowed in the sinkhole of stigma, families discourage them from speaking up and conceal illness from their

communities. Patients and caretakers experience this impetus for silence as a dismissal of pain and suffering. I understand suffering in silence – the sickle cell community's term – to be a consequence of the combination of witchcraft discourses around sickle cell and a broader taboo around pain and illness pervading their home and diasporic communities. As a result, people who live with sickle cell do not seek diagnosis. They conceal diagnosis. They keep their pain silent. Their pain is untreated. Their crises are untended.

We hide it. We hide the disease.

Most hide sickle cell in Canada, too. For most do not take part in the sickle cell community. Over six hundred patients live in Montreal. A microscopic fraction joins the community. As I am told, the majority of patients conceal their illness from their diasporic communities of belonging, so as not to be cast off. As opposed to Africa or the Caribbean, here they welcome diagnosis and hospital care – albeit partially, as mistrust of biomedicine lives on. Pressed down by fear of ostracization or shame, however, they seal sickle cell from sight beyond the hospital. They suffer in isolation. The people who do join the sickle cell community tend not to keep sickle cell under wraps in their diasporas, but suffer the consequences. Their communities are not always responsive. Hence the existence of the sickle cell community.

The sickle cell community forms a culturally liminal oasis where people may be granted respite from their similarly lonesome existence and share their suffering. Where they may seek shelter from the arid cold of the dominant culture, land of darkness. Where they might feel the warmth of African and Afro-Caribbean culture without its stigma. Where they are protected against both the violence of antiblackness and sickle-cell-related stigma. Where they develop empathic intimacies through the act of sharing suffering, and thereby lessen the "loneliness that accompanies sickle cell." Where they may keep each other company in times of need.

…

Cam has a cousin named Ade. He is twenty-five. Like Cam, Ade calls West Africa home. Like Cam, Ade has sickle cell. But where Cam's demeanour is eternally zestful, Ade's bearing is taciturn, almost aloof. He carries an air of haughty indifference that pairs nicely with his all black wardrobe. Like with Emma's vaporous daughter, I wonder if release from pain's world-rending shackles would gentle his moodiness away. Despite his seeming ennui with the peopled world, or

possibly his forcefully enfeebled presence within it, he attends events held by Crescent on occasion. Among those is a support group meeting.

During this particular session, conversation circles the necessity for the community to come together and talk about sickle cell. Ade interjects only once. “Okay, but why do we have to talk about it? I can live with my disease and not tell anyone about it. I just don’t get it.” Giggles go around, he does not laugh, he says nothing. It is hard to tell if Ade is acting the part of deadpan class clown or displaying artless puzzlement. His face is lifeless as stone.

A pain crisis strikes him at the end of the picnic I have depicted earlier. He is rushed to the hospital. I do not hear of him until a week later, at Alice’s.

Languid in the miserable heat, I sit cross-legged on her sinking mattress, slouching back against the bedframe. Alice is propped on her elbows at the bed’s other end. The apartment she shares with two West African newcomers is tiny and cramped. Cluttered on the nightstand are corticosteroids, painkillers, sleep medication, folic acid, and a vial of pink-and-blue hydrea capsules. The still air is laden with the acrid stench of boiled seafood laced with the heady sweetness of her roommate’s perfume. It is hard to breathe. Dying sunlight rills in through the drawn venetian blinds hanging over their one window. Alice’s tired eyes are half-shut against the slatted light as she recounts her week of migraines. Soon her phone lights up. Her eyes dip.

“It’s Ade,” she says.

“Ade?”

“Yes. He called a lot this week.”

This gives me pause. Ade is not the chatty type. “Does he like you?”

She gives a half-hearted laugh. “No. Remember, he tripped and fell at the picnic last week and had a crisis. He couldn’t walk for days and had to stay home all week.”

“But why call so much?” I have never seen Alice and Ade speak one on one before.

“I think he just wanted me to keep him company. He’s alone here, you know. He lives alone like me and has no family. We need to keep each other company.”

Alice and Ade are set apart from collective life but connect with each other, co-exist, within the margins they dwell in. They reach each other through the conflagration of their existing networks of relationships caused by the combination of exile and sickle cell stigma. They are each other’s only empathic company. Combined, estrangement from their adoptive land’s cultural coldness and the tenacity of sickle cell stigma in their diasporic communities

of belonging create and expand relationships between the people of the sickle cell community. Permit deeper touching through the sharing of the specific suffering wrought by the entanglements of sickle cell with antiblackness, cultural alienation, and stigma. They understand the depths of one another's suffering because their own is proximate. *They feel what I feel,* said Alice. *The community is like a family.*

"Kinsmen are people who live each other's lives and die each other's deaths. To the extent that they lead common lives, they partake of each other's sufferings and joys," notes Marshall Sahlins (2013, 30).[23] Partaking in proximate others' sufferings opens the possibility of forging kinship ties. I hear a few people call Crescent's president "the community's dad." Correlatively, many, including Crescent's president, refer to the community as a family. "The sickle cell family." They *know* one another's suffering, for their own is so strikingly similar. *It's a community that truly understands me,* said Tarah in the introductory chapter. A kinship appears to bloom through sharing suffering, which might be solidified by sharing a sense of mutual Afro-descendent genetic and cultural heritage – "Black blood." And, on the basic level of genetics, biological kinship ties do determine inclusion into the sickle cell community. Empathic ties of intimacy woven through sharing suffering thus bear the trace of kinship. People of the community are family: they feel what their peers feel, lead comparable sickled lives. They share genetic baggage, Afro-diasporic blackness, culture, and blood. They similarly feel the weight of antiblackness, the ache of cultural alienation, the insidious violence of sickle cell stigma.

That stigma constitutes a source of great suffering makes unanimity in the community. Many labour to spread awareness about sickle cell in their diasporas to dampen stigma's intensity, insisting that sickle cell is purely genetic, actively resisting the cultural taboo around illness. One location in which the collective effort unfolds is church. Community leaders target its participants' churches for blood drives and a few fundraising events. As I exit the field in late September, Crescent fittingly organizes one such blood drive in a Pentecostal church. In addition to collecting blood for patients, the blood drive aims to raise awareness in the Black community

[23] To be sure: I do not swear theoretical fealty to Sahlins's conceptualization of kinship. He posits interpersonal communion between kinfolk, and I do not (of course, my own perspectives on interpersonal alterity are informed by Western philosophical thought). I bring him in because his expansive conception of kinship leavens my reflections. I find quite illuminating his proposition that knowing another's suffering like it is one's own forges kinship connections.

about sickle cell and the chronic blood shortage. Choice of venue is not accidental. “We bring blood drives to the community,” Crescent’s president tells me once. The Black community.

We are already aware that blackness threads through the lattices of the sickle cell community. During our long talk, Aisha says to me: “This is part of who we are, as Black people. We are a community of faith, and faith cannot be dissociated from our lives.” Faith is indeed central to immigrant communities both African and Afro-Caribbean (Mooney 2009). Religious communities are protective spaces that offer institutional support to confront a new cultural environment, and narratives of hope to help make sense of their collective struggles (Mooney 2009, 39). Congregations are important meeting places for immigrants, to which they turn to acquire a sense of belonging in the face of wider social isolation (Mooney 2009). It should not startle, then, that faith would suffuse the sickle cell community. *Amens* peppering interactions have already hinted at God’s involvement with sickle cell. Faith is, Aisha implies, indissociable from their illness.

Retaining the thesis’s fragmented narration, the third chapter descends from a bird’s-eye view. It pays close attention to two sickle cell moms, Beatrice and Emma, and their twined experiences of God and sickle cell. While the saturation of the sickle cell community with the Holy Spirit can hardly be overstated, a sweeping view would afford an inadequate aesthetics. Modern Christianity is deeply introspective. It revolves around individual belief (Asad 2008). Faith’s inner orientation is distinctively strong among evangelical Christians (Bielo 2011; Luhrmann 2012). The sickle cell community so happens to be teeming with evangelicals. Sinking into the inner lives of a select number of evangelical individuals, if only partially, seems de rigueur if we wish to understand the entanglements of sickle cell and faith. We set foot in the world of evangelism through the electric heat of a Pentecostal service.

Chapter Three

That's how we know God is alive.
– Emma, upon learning a sickle cell patient has been spared from COVID-19.

Behold, God is my salvation; I will trust, and not be afraid: for the Lord Jehovah is my strength and my song; he also is become my salvation.
– Isaiah 12:2

God always ends up delivering me.
– Beatrice.

Three women sing on the stage.

O Lord, our saviour –

They sing softly, slowly, eyes shut, a hand raised to the vaulted ceiling.

My strength is Jesus our saviour –

Trickling from overhead speakers, discordant piano notes kiss their escalating voices.

My voice raises to you –

The women sway to the broken rhythm as if on a rolling boat.

Through his death he saved me –

The rocking motion spreads to the sea of congregants.

From his life he gave me –

Together they sing louder now, as the Holy Spirit moves down upon them.

Of your will you will dispose of me –

The man in the front row falls to his knees, head drooping to his chest.

My being belongs to you –

The women behind me weep, arms upraised.

Glory to God, the eternal –

The garbled murmurings of Beatrice next to me.

Jesus, Jesus, Jesus, Jesus, Jesus.[24]

Lyrics rolling on two projector screens flanking the stage run their course. Music melts into an electronic hum. The low buzz surrounds us like a swarm of invisible bees. The three women chanting fall into jumbled whispers at once. The one nearest me mouths Jesus's name over and over and over and still she sways on her feet and still her eyes are closed. Chills go skittering up and down my back, scuttle down my arms, peter out through my fingers, I swallow, shift in my seat, my hands grip my thighs, my palms' wet heat passes through my pants.

"Jesus!" A woman's yearning voice resounds from the back of the tightly packed church. "Jesus! Jesus!" she implores through wet sobs.

Startled, I whirl toward the wailing. My gaze swoops over the dozens of heads bobbing to their chests and back to the sky. My eyes are open, but nobody else's are. Their cheeks are dewed with tears or sweat, or is it both? Cool air blows from above but the room's mugginess is intolerable, drenched with the musky smell of sweat. The breathy vibration swells and swells and a young pastor steps onto the pink-carpeted stage for sermon and as if on cue the disquieting hum fades and dies. A strange soundlessness hangs in the air. Those who have been standing or kneeling sit down on the cushioned pews. No words or glances traded.

With her arm brushing against mine, Beatrice draws a breath and flips open a worn notebook on her lap. I give her a subdued smile, a poor attempt at masking my wonderment at the collectively dissociative trance she has awakened from – never before have I attended a Pentecostal service. Last time Beatrice and I spoke, she encouraged me to accompany her to Sunday mass so I could feel the Holy Spirit and commune with God. ("You need that first experience of God!" she told me, a recitation of evangelism's experiential emphasis.)

Behind us – at the start of the service Beatrice dragged me by the arm to the second row – people open their Bibles, many of them on their phones. As the three singers step down from the stage and take a seat right in front of us, the bearded pastor thumbs through his notes laying on the lectern. The two large screens now read verses from the Book of Mark. In a hybrid of French and Creole, he vividly tells the tale of Jesus's manifold sufferings, dissecting the gruesome

[24] I did not have a recorder going during praise, so I scribbled the fragments of lines I could remember in my journal afterwards. Small parts were also in Haitian Creole, and I did not understand every word. The flow of this ten-minute song is rendered imperfectly.

details of his agonies. The pastor is equal parts gifted storyteller and authoritative interpreter. He is deeply moved by Jesus's sacrificial tribulations, every misery he has suffered to save us (*our saviour*). How intimately human the Son of God is, he is saying through a river of tears now. He has known the same pain, tortures, humiliations, and anguish as us. Christ, God-on-the-earth.

Light of the world.

Beside me, Beatrice scratches down a few notes and hums intermittently at the wisdom her pastor imparts. Kindly she whispers Creole to French translations in my linguistically challenged ears. All congregants are of Haitian descent, she informed me before we entered the lofty auditorium. "We go where we are comfortable."

As the pastor sermons, snuffles and unrepressed sobs are unleashed with increasing intensity behind me. I dare not turn to scan the room. Beatrice, though, is cool and collected. I suspect my presence sedates her. She once mentioned speaking in tongues and thrashing and flailing uncontrollably during services. Slain in the Spirit.

The pastor now recounts the story of Job, an innocent man whose faith in God did not waver in the face of unthinkable tragedies. Job never doubted God. He never cursed him. He always abided by God's inscrutable plan. The longer the pastor describes Jesus's pain and Job's miseries and God's love the more his breath catches in his throat and his voice grows ragged and broken and he finds himself unable to finish some sentences as he surrenders to the passion.

"No suffering is too bitter, no suffering is too bitter" he repeats in a hitching voice. He aspires to withstand suffering like Job. God's plan is impenetrable, but his loving presence is eternal. In times of suffering, we must turn to God without trying to understand his logic and yield to his love. Just like Job. "God did not say we would not suffer. He would not impose suffering on us that he didn't think we could bear." At this, Beatrice prods my shoulder with her elbow and gives me a meaningful look.

"See, this is what I told you about," she says with a hand cupped to her mouth.

…

Though possessed of a gregarious spirit, Beatrice does not go to church to mingle with other congregants. She is fortunate. The stigma attached to sickle cell is not as strong in her church as it is in many others' in the sickle cell community. Religious communities reinscribe sickle cell

stigma, as I describe below. The cultural norm of silence, or taboo, attached to illness ripples across their congregations. Or, if illness is discussed, it is embedded in theodicies of suffering that, unlike Beatrice's, affix blame on the sufferer's faults. This only fuels the shame and guilt that accompany stigma.

"There's trauma in religion," Tarah, a patient, tells me. "When people learned I had sickle cell, the first things they told me was to go to church and pray it out." So she did. Nothing changed. People's responses to her prayers' failure instilled in her a feeling of personal guilt for her suffering.

"Whenever I got sick, I was so religious that I thought I had done something wrong, that God was punishing me, that's why I was born this way. It was just negative, so I took my distance from religion. I wouldn't go back because it's just negative. When you're outside the norm, they think you come from darkness!" She titters uneasily. "They think you're not normal, that Satan is inside you. It traumatized me…I thought I was a bad person for a long time." In light of her trauma, she maintains a personal relationship with God but stays clear of church. There, her illness is conflated with evil and death. She is cast as a creature of the shadows. Many people in the sickle cell community experience this sort of alienation from religious communities. Evangelical ones especially. The people of the community are robbed of the sense of belonging and institutional support immigrant communities find at church (Mooney 2009). Another layer of social exclusion piles on. Neglected by the antiblack world, estranged from Canada's cold culture, alienated from their home and diasporic culture, and excluded from their religious communities.

Beatrice's problem has to do less with stigma than her fellow congregants' infinitely tiresome nature. She abhors church gossip and slips away as soon as service ends. She rejects her church's promotion of ascetism, defiantly dons flashy jewelry, trendy clothing, precarious footwear, makeup, and twists her long braids into architecturally impressive hairdos. She loathes ritualism above all. It is one reason she has long abjured Catholicism for evangelism. Jokingly she compares Catholics to "little calves sucking up their mother's milk." She would rather not be fed gospel like a witless little calf. (The second reason she drifted to charismatic Christianity is Quebec Catholicism's coldness. "In Haiti, the service is warm. Here it's cold," she says. "I was aching and wanted my country back." She gravitated to her people and their warmth, who cluster around evangelical churches.) Despite her many discontents, Beatrice seldom skips mass. At

church, surrounded by close to a hundred people, the Holy Spirit pours into her more smoothly (Isa 32:15), her connection to God ignites swiftly, "it catches like fire."

Like Beatrice, a large number of individuals in the sickle cell community share the evangelical faith. I meet a few Catholics and Muslims, too.[25] All coexist peacefully. But evangelical Christianity dwarfs other faiths. On this account, this chapter pays special attention to sickle cell's intertwining with faith. I concede this decision is bound to muffle other perspectives. Yet in addition to their greater number, evangelicals discuss faith with me more readily. They are quite outspoken about the place of God in their lives. Because I possess insufficient material to draw conclusions about other faiths with any modicum of confidence, I anchor the chapter in boisterous evangelism.

Evangelism comes in many shapes and sizes. Pentecostalism is one evangelical branch to which many in the sickle cell community adhere (a minority are Seventh Day Adventists). Adding to the multiplicity, folk and scholarly definitions of evangelism and its various divisions vary (Luhrmann 2012; Robbins 2004). Nonetheless, common threads weave through all evangelical styles. Evangelicals first and foremost receive gifts of the Holy Spirit. These include curing, prophecy, the working of miracles that bend the laws of physics, and, for Pentecostals, speaking in tongues (Bowen 1996; Luhrmann 2012; Robbins 2004). As Beatrice reminds us, speaking in tongues signals the Holy Spirit having entered the body: "You are filled with his presence." Evangelicals also lean toward Biblical literalism. They read the Bible as a rendition of historical truths. Evangelical doctrine is grounded firmly in the Bible. That is my rationale for consulting scripture, the King James Bible, to contextualize my interlocutors' stories. Finally, nurturing a personal relationship with God is the core of evangelism. That relationship is, in fact, the "*sine qua non* of salvation" (Bowen 1996, 128), as I discuss later on. Like Beatrice, these Christians spend their lives nurturing personal relationships with God.

I make acquaintance with Beatrice and her sick daughter through Crescent. We first speak while waiting for the bus that will take us to sleepaway camp. Beatrice and her daughter go every year, I learn as the moist heat steams us alive in front of Crescent's office. A crowd of forty people and their outsize suitcases has formed on the sunstruck sidewalk, breaking the flow of harried-looking pedestrians.

[25] Considering that many West African countries are predominantly Muslim, I encounter surprisingly few Muslims in the community. Evangelism is concentrated among persons of Afro-Caribbean origins, but not exclusively.

The yellow bus trundles over, at long last. We haul our bags in the below compartment and climb aboard the stuffy cabin. Crescent's president gets on last and inaugurates the trip with a prayer, "God bless this trip," a chorus of *Amens* in response, into the wilderness we are herded.

Clouds abduct the sun next morning. Heavy rain comes pouring down on our shared cabin by the lakeside. For two days deluge pelts the lake and the lake grows black and frothy and swollen. We are cramped inside the chalet and have only each other to pass time. I am bunking in a small room with Beatrice's daughter, as well as Emma and her daughter. All are friends. All are chatty. We idle the rainy doldrums away with endless conversations.

One of those occurs on an early afternoon. Beatrice, Emma, and I are closeted in our bedroom. Sooty light creeps in through the one window, the overhead lights are switched on but weak, the white walls appear ashen. Emma's daughter slips in and out of consciousness on her top bunk, lying lost to her pain as she will until morning. Emma sits on the hard mattress beneath her daughter while I stand slouching against the closed door. It is thin and poorly muffles the racket of kids driven to madness by confinement, hurtling up and down the stairs, screeching in delirium, plunking away on a piano downstairs. Beatrice is exuberant and restless like always. She jitters about in the gap between bunkbeds and talks and talks and she talks so fast.

Just now she chitters enthusiastically about her recent purchase, a TENS machine. It is a bunch of electrodes that emit small currents when placed on painful areas. It has helped her daughter, she says, but it goes for three hundred dollars. Emma has never heard of it. She tries Beatrice's device on her own arthritic back. Her eyes widen in shock. Immediately she promises her sleepy daughter to purchase it. "I'll get it for you," she says looking upward. "As soon as I have the money I'll get it."

It is then that Beatrice and Emma begin chirping on about faith, as they are prone to do every so often. By August, I have long discerned the Holy Spirit pulsing through the sickle cell community. I am not taken by surprise when their three-person'd God – Father, Son, Spirit – slinks his way into our chat.[26]

The two mothers and their daughters are evangelical. Both greatly dislike their church communities for different reasons. While Beatrice's patience for church drama is paper-thin, Emma feels alienated from her church. Sickle-cell-related stigma oozes over her congregation.

[26] I erred in not recording many of our informal talks, however. I cannot reproduce this one perfectly, even if I jotted down some of their words in my notebook.

Her church associates illness with sinful behaviour and deficient faith, a discourse resounding across a number of evangelical churches (Bowen 1996). Beatrice and Emma thus keep their distances from their disagreeable congregations. But their faith has not wavered. After all, "church is within each of us," Emma is saying now.

To the pair, faith is not about religion: people, rules, and rituals. Reverberating with the "inner worldly posture" (Bielo 2011, 268) of evangelism, Beatrice and Emma are concerned first and foremost with cultivating a close relationship with God. This ever-evolving relationship with a being that is immaterial, and yet related to as a person, is the core of their faith. I find Tanya Luhrmann's (2012) image of a childhood imaginary friend (but real) helpful to wrap my head around the kind of social yet inner relationship bonding evangelicals to God. He is a trusted but invisible friend, ever present by their sides, always lending a listening ear, privy to every detail of their inner lives. The profound sense of peace, of being cuddled and loved and sustained through hardships, is what believers glean from this relationship, Luhrmann (2012) says. She further suggests that, with time, believers develop an emotional dependency on God. Beatrice concurs: "I believe, and the more I believe, the more belief becomes a drug. I couldn't live with a void inside me. My body is just too used to the presence of the Spirit."

"It's like having a boyfriend," Beatrice says to me now, as we are cooped up in our bedroom. I just asked her and Emma to describe their relationships with God. "It's like any romantic relationship. It manifests itself differently for everyone, and like any relationship, it requires work and effort – but it's never a burden!" she specifies, giggling. That relationship gives her a profound sense of serenity. "The inner peace that God gives me feels like – you know when you eat ice cream in the summer? When it's so hot and the ice cream goes down your throat and…" Beatrice exhales yearningly with her eyes closed, traces her fingers down her throat and rests her open palm against her heart. "That's the peace of God."

God also speaks to them. In fact, he talks to everyone through various means. Beatrice hears God's voice auditorily. God also communicates with her through dreams and visions. He even sends angels sometimes. Alternatively, God speaks to Emma through other people and nature, because God is both immanent and transcendent, palpable and personlike at the same time that he is spirit. Emma is saying, God is outside herself, she sees and hears him in others and in the trees, he is in the wind, the sun's warmth on the skin, the bees, she can feel him inside her body too, he speaks in feelings and sensations, remember that God is three in one, remember that God

is omnipresent, he is everywhere, he talks to me all the time and he is calling you too and he loves you and desires to pursue a relationship with you.

A question rushes at me as words come tumbling out of her. I overheard Emma and Beatrice discuss Emma's daughter the night before. They were curled up side by side on a threadbare sofa, wrapped in a cocoon of light. The central hall was lightless but for the amber glow about them. I captured only scraps of what they were saying. Beatrice mentioned Emma's daughter's name and Emma followed with: "God is good, God is good." Her mini crisis had begun earlier that evening.

"But what about sickle cell?" I cannot help but ask Emma and Beatrice now, in the white heat of our bedroom conversation. "How can you explain sickle cell if God is good?"

"It is part of God's plan," Emma says with sincere earnestness while she lathers lotion on her arms. As the air fills with coconut, she explains that God has hatched a plan for each of us. He has drawn a clear path he wants us to follow. "God knows where he wants you to end up," Beatrice adds. "It is up to you to follow his plan or deviate from it." Sickle cell is part of his plan for them and their daughters, but God's will is cloudy. We should not grasp for complete understanding, because his ways are higher than our ways. She shrugs, communicating elementary self-evidence.

I have already heard the phrase "his ways are higher than our ways." It was uttered at the sickle cell symposium depicted in the first chapter. Aisha invited a pastor to the event. The latter recited a prayer of hope and closed it with those very words. They are verses from the Book of Isaiah, which is quoted widely in evangelical circles (Luhrmann 2012). The book is replete with prophetic messages of hope for God's salvation. To be precise, Isaiah 55 (chapter 55) renders God's invitation to come to him and accept his promise of faithful love, peace, everlasting joy, healing, and comfort to all who "thirsteth" for spiritual "waters" (Isa 55:1-12). "For my thoughts are not your thoughts, neither are your ways my ways, declares the Lord. For as the heavens are higher than the earth, so are my ways higher than your ways, and my thoughts than your thoughts" (Isa 55:8-9). Hence Beatrice's and Emma's assertion that they should not attempt to understand God's will. Doing so would be in vain, because God's sovereign plan is inherently higher than human comprehension. All they may do is accept God-ordained suffering with serenity. Abide in the certainty that their suffering has divine purpose. That all is as it should be.

That all will be well: God is "the restorer of paths to dwell in" (Isa 58:12). He brings salvation onto those who trust unquestioningly. Like Beatrice and Emma.

"One encounters this kind of foundational certainty often in these Christian lives," writes Tanya Luhrmann (2012, 58) in her ethnography of American evangelism. She continues, "the technical term for it is *noetic*: a sense of knowing somehow deeper than everyday knowledge, bedrock rather than topsoil" (ibid.). This noetic certainty in God's all-powerful benevolence saturates my encounters with people in the sickle cell community, though small exceptions exist among non-evangelicals. God's unconditional love is the bedrock of their world, a basic truth that underpins their ruminations about illness and suffering. And Beatrice and Emma's God is not a remote behemoth. He has retained a sense of supernatural elusiveness about him (*he is everywhere*) but shed the mantle of a punishing judge. Theirs is a God who is relatable, personlike: friend, confidant, father, even boyfriend. "Some days I cry before him, some days I stand up to him and yell, some days I'm so angry I don't want to hear anything about him. But we're good buddies," Beatrice says later in the summer. "He's my friend. When I need the friend, I call the friend. When I need the dad, I call the dad." Beatrice and Emma convey precisely this kind of unwavering faith in God's personalized plans for them. They do not question his divine ways, because God is fundamentally good.

"Aren't you upset with him?" I counter while we chat in the bedroom. Their equanimous acceptance of divinely inflicted suffering appears to bypass the shortness of our human temper. How can they look so serene in the deep of illness, how can they be convinced of God's goodness, how can they find solace in his elusive love? It astonishes that God's imposition of suffering onto their lives does not make their blood boil.

Synchronously they laugh at my perplexed frown. Naturally my frown deepens. Oh, yes, they say, casting knowing glances of amused understanding at each other. They remained angry at God for a long time, but time has tapered their anger. "That feeling is gone now," Beatrice says, because she knows God has thrust illness onto her life to give it purpose.

A decade ago, when her daughter was a toddler requiring frequent hospitalisations, Beatrice would fall to her knees and plead to God, "why, why, why her, she's innocent, I'm innocent, what have I done to suffer like this, why are you doing this to me, your own daughter?" One night, things changed. She was praying to the lilt of Christian music, kneeling before her home altar by the fireplace. Weeping her aches unto God. He spoke to her then ("remember, I am

auditory"). He sent an emissary angel, who whispered in her ear the purpose of her suffering. God cast illness upon her daughter so Beatrice would help others who are sick like her. Since then, Beatrice has remained unyielding in her conviction that helping her peers in the sickle cell community constitutes the personalized life trajectory God has traced for her. As she says, it is up to her to follow it. By virtue of her unbending trust in his plan, she does. "I know he's in control." As it so happens, next month she is organizing a fund-raising event in collaboration with Crescent to propel biomedical research.

Emma has been humming along in assent. Just then she looks my way and nods without word, the batter of rain against the ceiling puncturing the pocket of quiet that sets in.

…

Clouds free the sun on the day following our bedroom chat. Sky and water flare blue again. Mirth returns. Alive in the blooming afternoon heat, flocks of campers fly to the teensy beach in front of our cabin. Our sickle cell group arrives strategically early after lunch. The beach is not too crowded yet, so all can squeeze their towels or folding chairs on the wet strip of sand.

I settle next to Emma at the outer rim of the beach, underneath a shady tree. She is watching her daughter who sits a few feet away. Her daughter's head is tilted in the sun's direction, she leans back on her arms, her eyes are closed, she does not speak, her pain melts in the brassy warmth (as she tells me later).

Emma and I sit in companionable silence a long moment. After a while a rustling sound comes from the wooded hillsides cupping the lake and the soughing of the trees moves closer and we are hit with a whoosh of wind. Hats are sent flying. The wind does not fall, it sours the air with its chilly breath. Emma's daughter rises to her feet and lopes up the puddly path to the chalet.

It's the wind, it's cold, Emma says when I eye her questioningly, wondering at her daughter's sudden retreat. She is seeking shelter indoors for fear of relapsing into a cold-induced crisis. Quickly our attention is pulled to the blur of flailing noodles in the lake's shallows.

"Do you think your daughter will ever be cured?" A spur-of-the-moment question to poke the silence.

Emma inhales, and exhales. “Yes. Yes, if I can be completely honest, it’s my dearest hope. I pray for it so often.” After another long breath, she says that even though sickle cell is incurable, a cure is possible because it will be God’s doing. “I cannot predict how it will happen, but it is possible, because you need to know that God cures in different ways. He cures people with sickle cell in different ways.” Cure can come about through new medical treatments or wondrous means. Even if medicine cures her daughter, it will be to God’s credit, “because medicine and doctors’ knowledge were given to us by God.” Thus Emma prays and keeps on praying. “But we cannot force God’s hand. His will must align with ours.” If he does not want her cured, he has his reasons. It is all part of God’s plan for her. “So I have learned to accept sickle cell.”

Integral to the evangelist – in particular the Pentecostal – ethos is the conviction of God’s power and desire to cure (Bowen 1996). Faith curing, or miraculous curing that is unexplained by medicine, occurs as an outcome of prayer. But, as Luhrmann (2020, 138) writes, “we cannot truly understand prayer if we insist that it is founded on a mistake: that people pray because they think that gods deliver the outcomes for which they pray, and that they are wrong.” An implacable truth of evangelism is that God has the power to heal any condition irrespective of medicine’s limitations. However, the faithful do not treat God as a fairy godmother, granting wishes with a whip of her magic wand. Prayers, Luhrmann (2020) claims, should be understood as conversations with God above one-sided requests. They function as ways of sustaining the connection, of increasing intimacy, of communicating desires and anguishes to God. Regardless of the reasons for prayers’ failure, God is always loving and compassionate. In fact, prayers’ failure is productive. The more prayers fail, the more people grope for God’s love and support (Luhrmann 2020). The closer to God they become. Sociologist Kurt Bowen similarly writes of a Pentecostal assembly in Mexico: “Sometimes healing was delayed or denied by God to lead a non-believer to conversion, *or to test and thereby deepen a believer’s faith*, as in the classic case of Job” (1996, 113; italics mine). Yet at other times, pastors and congregants found no apparent reason for lack of healing: “even for the faithful, God’s plans were sometimes a mystery” (ibid.).

Luhrmann (2012) also suggests that evangelicals embrace humans’ limited perceptual abilities in earnest. They, like Emma, yield to an eternal uncertainty about God’s ultimate plans for each of us. It is not theological understanding that is promoted in evangelical churches, but intimacy with God. I like Luhrmann’s way of putting it: “That old, old mystery – how little we understand, how much it confuses us, how drawn we are to the promise [of Gospel, or the

teachings of Christ], how repelled we are by its irrationality – is at the heart of this new imagining of God" (2012, 38). Evangelical churches push congregants to feel God as present, "theological precision be damned" (Luhrmann 2012, 89). Implied in this embrace of divine unintelligibility is protection against cognitive dissonance in the inevitable event of prayer's failure (manifested as the persistence of illness and suffering). God's ways are simply higher than ours. Therefore, we must accept illness and suffering as part of his sovereign plan. Emma is calm in her convictions. God is good. Suffering has divine purpose. Sickle cell is part of his inscrutable plan. Fundamentally, God possesses the power to cure sickle cell irrespective of science's limitations. The discovery, or perhaps more accurately the creation, of a biomedical cure would be his doing. Because God is "perfect in knowledge" (Job 37:16).

The words I exchange with Emma on the beach are not the first I hear that allude to the interlocking of faith and biomedicine. Echoing Emma, another sickle cell mom tells me, "I'm a believer, but I think that doctors' intelligence was gifted to them by God. So a cure can happen miraculously or through science – but mostly through science." She then embarks on an enthusiastic exposition of recent scientific advances and new curative horizons opened through genetic modification, visibly rejoicing in the possibility of our becoming "X-Men." Throughout, she stresses that "God is above everything," reiterating the biblical truth of God's omnipotence.

In the sickle cell community, God's and biomedicine's curative promises are conjoined. The "techno-scientific imaginary of cure" (Ginsburg & Rapp 2024, 29), or the belief in biomedicine's capacity to eradicate disease through scientific innovation, is pervasive in the community. Their embrace of biomedicine's curative powers, or what Mary-Jo DelVecchio Good calls the "biotechnical embrace" (2001, 399), does not puzzle. As DelVecchio Good (2001) writes, the medical imaginary is deeply imbricated into Western popular culture. As a result, the "salvation ethos that is fundamental to bioscience and biomedicine" (DelVecchio Good 2001, 407) envelops society at large – including the sickle cell community. By virtue of close connections to the medical establishment, the chronically ill subscribe more enthusiastically to the cultural power of medicine, and the salvific hope promulgated by the idea of biotechnical innovation (DelVecchio Good 2001). Foremost among culturally salient medical technologies is high-risk gene manipulation. Fervour for the curative possibilities of gene therapy has indeed swept over the sickle cell community.

For evangelicals, this inexorable certainty in cure seems to flow from an unswerving faith in God. In the community, the biotechnical embrace is indissociable from God's. Because ultimately, the power to correct disease is in his hands. *God is above everything.* He has foreknowledge of everything. While the cultural power of biotechnical innovation has firm footing in the sickle cell community, the ultimate arbiter of salvation is God. Biomedicine becomes one (likely) vessel among many through which he may gift patients with a sickle cell cure. Which means a non-biomedical miracle remains imaginable. "The God she knows is the Eternal One Who Heals," Beatrice tells me with reference to her sick daughter.

The sickle cell community is abuzz with stories of miraculous curing, or the erasure of sickle cell bypassing biomedical treatment. Unvaryingly, talebearers are of evangelical disposition. Details are always murky, though. The stories' vagueness makes me wonder if they are only rumors. Someone's friend has been cured by God, and they never had a single crisis afterwards, never needed medication or treatments. Someone else remembers a like story of miraculous healing they were told years ago by friends of friends. Once I meet a middle-aged woman who claims to have been cured in such a way. At twenty-eight she miraculously stopped having crises. She provides few other details. Listening to her, I am seized by the feeling that she takes pride in her miraculous cure. Two other patients, including Alice (who is Muslim), listen in, rapt. They appear enthralled by her short tale, envy leaching from their goggle eyes and intermittent gasps.

"I still have a few years until I'm twenty-eight," Alice tells me with a longing sigh later that day, still thinking about the woman's story. No sarcasm, no humour, in her voice. No smile on her face. "I'm putting my fate in God's hands."

God, patron of all cures, also offers salvation of another kind to evangelicals of the sickle cell community. God saves *from,* and also *through,* suffering. If I may swipe Beatrice's turn of phrase, the latter is a kind of salvation that feels as good as an ice cream cone on a hot summer day.

…

God is good, God is good.

Beatrice and I are sitting on the curb facing her church a month after the camping trip. Sunset pours a river of molten copper over the parking lot, incarnadines the church's brickwork. The air is hazy with the day's residual heat and the busy road behind the curved building wobbles. Cars parked glint in the bleeding light – I have to shield my eyes with a hand as we await the end of her daughter's Bible studies. Beatrice drums her long nails against her phone case, growing impatient. It is Friday and she has more fun plans but the event stretches on until sun becomes moon.

She revels in chatter, Beatrice, so we chatter into the balmy night. During our short stay in the mosquito-ridden woods a month prior, Beatrice claimed that God bestowed sickle cell upon her so that she would help those who suffered like her. She did not expand on the matter, and I want to better understand. Happily she invites me on a loopy interior journey.

God creates each of us for a specific purpose, she explains. He endows us all with different gifts, but they are not intended for personal use. We must use God's gifts to serve others. "He created me to accomplish certain things that would be impossible without him. I was created *for* something. That's why he gave me the gift of self-sacrifice. Whether it's at work or with sickle cell, I have this compassion that allows me to do more for others. If someone needs help, I will help out for free, because that gift is part of me. He has created me to give. To help others, you see. It's part of my DNA."

This altruistic gifting of personal suffering to the sickle cell community resurges in other people's narratives. "There's a pastor who often says that your suffering is an opportunity to help others who share the same suffering," a sickle cell dad told me a month earlier. "Helping the community became natural, and I do so without anyone telling me I must help people who suffer from sickle cell. I just help them." His wife, who was sitting next to him, added: "Don't waste your pain, use it for others. Don't waste it. I use my pain to do some good, to help others who hurt like I do."

Now, eyes set on the church looming bloodred before us, the question I asked Beatrice during the camping trip comes to my lips. "But how do you explain your suffering and that of your daughter?" I wonder what response she will produce a month later.

"Suffering is part of human life. It's part of us," Beatrice replies without missing a beat. "Without darkness, light doesn't exist. Without light, darkness doesn't exist. There needs to be balance between them," she says casually, hinting at the Christian theology of light and

darkness.[27] "If everything had gone well in my life, there are things I would never have known. I would not be the woman I am today with all of this baggage. And then I would not have had the same experience of God."

Her daughter's illness has allowed Beatrice (as well as her daughter, according to Beatrice) to develop empathy and grow strong, but more fundamentally to work on her relationship with God. To learn how he responds to prayers. To strengthen her connection with him. To accept suffering as part of her fate, she says.

"God will never make you suffer if he knows you cannot handle it. If he makes you suffer, you open your eyes and will spend less time suffering. The amount of time you spend suffering, in pain, it's your connection to him you will work on. You will learn a lesson. It's God's way of helping you progress in life."

Beatrice is speaking with the most didactical of tones, perceptibly keen to impart Pentecostal wisdom. This truth is unshakable: God has made her suffer to tug her closer to him, and to nudge her to use her gift of self-sacrifice in service of others in the sickle cell community. "He knows what's good for me."

As intimated in this chapter's opening, Beatrice seeks to emulate Job's serene submission to God-ordained suffering, not unlike her pastor. She refers to Job's ordeal often during our chat. The Book of Job does not depict Job's protracted suffering as punishment for sin. In this sense, the book is a rejection of theodicy, for suffering is *not* meted out by God as punishment for sin but as a trial of faith (Levinas 1998, 241). Goes the story: "There was a man in the land of Uz, whose name was Job; and that man was perfect and upright" (Job 18:1). One day, tragedy struck. Upon learning of his ten children's deaths, Job sank to his knees and worshipped. "And he said, 'Naked I came out of my mother's womb, and naked I shall return thither: The Lord gave, and the lord hath taken away; *blessed be the name of the Lord*.' In all this Job sinned not, nor charged God foolishly." (Job 18:20-22; italics mine). Like Job, Beatrice reckons that her suffering is not divine retribution for sin, but she also knows God to be the source of her suffering. Through

[27] "Moreover, *the light of the moon shall be as the light of the sun*, and the light of the sun shall be sevenfold, as the light of seven days, in the day when the Lord bindeth up the breach of his people, a*nd healeth the stroke of their wound*," proclaims the prophet Isaiah (Isa 30:26; my emphases). In both Old and New Testaments, God's arrivals and doings are associated with waxing light. Incidentally, that is a part of my inspiration for baptizing Montreal's sickle cell association "Crescent": a crescent moon, sickle-shaped harbinger of light by which its participants walk through darkness, to paraphrase from the Book of Job (Job 29:3). Crescent moons have strong religious connotations in Islam as well. (I thank my advisor for reminding me of this later.)

suffering, Job continued to trust and rely on God wholeheartedly. Like Beatrice he lamented through prayer, of course, but never did he curse God. Nor does Beatrice. *God is good.* The wisdom to be gleaned from Job's ordeal is that God is omnipotent, God doles out suffering to test and deepen our faith, and God teaches us through suffering. Beatrice's steadfast faith in God's sovereignty, her noetic trust that he is in control, that "no purpose of [his] can be thwarted" (Job 42:1-6), allows her to find solace and purpose in her suffering.

"So the disease is almost a blessing…" A shade of hesitation passes over her. She fumbles for words, fingers her phone charm. The sibilant sound of the nearby road sucks up the short silence. After a second, she appears to make up her mind. She says decisively: "It allows me to strengthen my relationship with God."

Pulsating through Beatrice's meditations on suffering is the evangelical logic of salvation, the conviction that suffering contributes to her salvation. Unlike less flamboyant Christian eschatologies, evangelical salvation is not postponed to the afterlife. That is, redemption is not granted or denied at the pearly gates. It is now. Right here in our clayey world. Notions of heaven do have currency among evangelicals, but the latter achieve salvation as bone-and-flesh individuals. Being "saved," or "born again," is predicated upon first establishing, then sustaining and strengthening, a personal relationship with God (Crapanzano 2003; Bowen 1996; Luhrmann 2012). "Their hope for salvation … is not open, as it is for Catholics, " writes Crapanzano (2003, 8). "Evangelicals live in a world in which salvation cannot be achieved through good works" (ibid.). Salvation unfolds within the lives of the "saved" within our material world, through an ever-stronger faith in God. Sociologist Kurt Bowen concurs: "the essence of salvation is the achievement *and maintenance* of a personal relationship with the supernatural or God … Salvation is achieved by faith, not right action" (1996, 103; italics mine). Faith does lead to good action, Bowen (1996) notes. Altruism is, after all, a core tenet of the Christian faith.

Experiencing God as an intimate, loving presence *is* the emotional reward constituting evangelical salvation. Here emotional reward names sustained peace of mind, joy, protection, and tranquility (Bowen 1996; Luhrmann 2012). Ice cream in the summer. And attainment of personal salvation is "the end game" (Bielo 2011, 279) of evangelical lives. It is *because* sickle cell suffering has helped Beatrice strengthen her relationship with God that is has been (almost) a blessing in her life. She tells me, "God places obstacles in your path to see if you come to him." Without suffering, she would not have experienced as profound a communion with the divine.

Her faith would not be as strong. She would be a lesser person. Her suffering takes on an immediately, this-worldly salvific force in stirring her to nurture her relationship with God and strengthen her faith. As Bowen notes, the certainty of salvation sinks away if the faithful does not cultivate this inner relationship constantly. Beatrice's labour is, in this evangelical sense, perpetual. Suffering furthers this life-long effort to deepen her faith: working on her connection with God, in her words.

The religious dimension to her suffering's salvific force does not seem to transcend the earthbound world. That is, her individual suffering's salvation is not found through its interruption in the afterlife. The telos of her suffering is not to be personally saved from suffering, not to eventually soar to heaven. Not once does she hint at the final judgment, or the second coming of Christ. Nor does she allude, not even subtly, to any notion of heaven and hell, to any eschatological redemption she may earn from her suffering, or to theodicy (suffering as punishment for sin). Nor does Emma. Nor do any other evangelicals. Nowhere does the word "heaven" pop up in my field journal.

In hindsight, I have been remiss in not prodding about eschatology. Remissness aside, Beatrice and her brethren never attribute an eschatological dimension to their suffering. I have prolonged conversations about faith with evangelicals. It seems to me that, had eschatological redemption held a significant bearing over their understandings of suffering, it would have surfaced. In fact, my intuition tells me they would recoil from the idea that their suffering opens heaven's gates to them. I stand in awe at their selflessness. True, they benefit from their suffering. It strengthens their relationship with God. Their personal suffering is salvific in this sense. Yet, generally speaking, evangelicals emphasize the altruistic purpose suffering has granted them. *They suffer primarily for others*: to mellow their peers' suffering in this peopled world. Not to transcend their own, either in this earthen world or God's celestial dwellings.

Here a third dimension to religious salvation swims into view. God's promise of cure is the first. God's trial of faith is the second. The third kind of salvation is imparted *by* Beatrice, *by* Emma, *by* people of the sickle cell community themselves. They suffer to save their community from sickle cell suffering. Doing so requires disentangling sickle cell from antiblackness and cultural stigma.

…

The first two chapters bring to the fore critiques of nefarious social forces. People of the sickle cell community, including evangelical Christians like Beatrice and Emma, similarly understand social forces (antiblackness and stigma) to be sources of suffering. But when it comes to faith, suffering is enlisted into the telos of Christian salvation. God has bestowed suffering upon them as a gift. We find the coexistence of two antipodal views and experiences of suffering in the community, namely social suffering and redemptive suffering. From my experience, social critique is stronger among the less religiously inclined: Aisha and Cam, for instance. Nonetheless most evangelicals, all very religious, decry racial discrimination and stigma at the same time as they impute their suffering to God and find a sense of purpose in their illness.[28] Attending to evangelical Christianity's quirks helps us partially resolve the paradoxical coexistence of social and redemptive suffering.

As may have surfaced through my interactions with Emma and Beatrice, evangelism has individualizing propensities (Luhrmann 2012; Robbins 2004). It prompts followers to enlarge their innermost worlds, strengthen their individual connection to God. It bears repeating also that evangelism tends not to promote theological analysis. Evangelical churches incite congregants to *feel* God's loving presence intimately, ecstatically even, and to bridge theological gaps with their imaginations (Luhrmann 2012). It is like Emma says: God's ways are higher than our ways. Beatrice's darling Book of Job likewise advocates intellectual resignation to humans' lowly incomprehension. It closes with Job addressing God: "I know that thou canst do every thing, and that no plan of yours can be thwarted. 'Who is this that hideth counsel without knowledge?' Therefore I have uttered things I understood not; things too wonderful for me" (Job 42:1-4). *Without knowledge. Things too wonderful for me.* In this passage, Job refers to unwise statements uttered in the throes of suffering, questioning its purpose in a misguided way. The chief lesson I retrieve from the verse is that humans ought to surrender to their lack of understanding of God's will, unquestioningly so. "God is great, and we know him not" (Job 36:26). All we know is God spreads his light upon the world. Not when, how, or wherefore. "Great things doth he, which we cannot comprehend" (Job 37:5). Ultimately, the Book of Job ends with God delivering Job from

[28] So do Catholics and Muslims in the community, though God's plan is distinctive to Protestantism. However, as mentioned I do not have the necessary details to construct an argument about the mixture of sickle cell and their religions' theodicies.

suffering. Only after Job has learned his lesson – unshaking faithfulness in the face of appearingly senseless suffering.

Combined, evangelism's individualizing leanings and embrace of God's unknowable will transform personal suffering into a learning opportunity (Luhrmann 2012). Here is a fundamental nuance. For Beatrice and Emma (and other evangelicals I meet), suffering takes on a redemptive cast only when it concerns the self. God's plan seems to end at the boundary of the (Christian, self-contained) self. It falls short of accounting for the yawning well of suffering that is the sickle cell community, or ills of a larger magnitude. Correspondingly, the faithful I know do not view their peers' suffering through the same salvific optic as they see their own. Though their personal suffering is meaningful, never is their peers'. If we remember, one purpose of their suffering is to altruistically dedicate their lives to alleviating their compatriots' suffering.

Emmanuel Levinas's perspectives on suffering rise to mind here. Ferried by his thoughts, I understand that Beatrice's and Emma's suffering is "meaningful in [them], useless in the other" (1998, 100). Levinas of course rejects all theodicy, religious and secular. Writing in the shadow of the Holocaust – and couching his reflections in its unutterable cruelties, like Blanchot – Levinas views suffering as intrinsically senseless.[29] Nonetheless, he allows the possibility for suffering to become meaningful to individuals: "there is a radical difference between the suffering in the other, where it is unforgiveable to me, and my own experience of suffering, whose constitutional or congenital uselessness can take on a meaning" (Levinas 1998, 94). Useful in Levinas's philosophy is the split he cleaves between individual suffering (which can be meaningful) and the other's suffering (which is useless). When great suffering befalls the other, it cannot be rationalized plausibly through theodicy.

In its inherent lack of sense or purpose, the other's suffering makes an ethical demand of altruistic responsibility from the witness. Levinas: "Is not the evil of suffering … the original call for aid, for curative help, help from the other me whose alterity, whose exteriority promises salvation?" (1998, 93). The cry for help, he continues, constitutes the "original opening toward merciful care … through a demand for analgesia, more pressing, more urgent, in the groan, than a demand for consolation or the postponement of death" (ibid). A "beyond" (Levinas 1998, 94)

[29] Blanchot's and Levinas's writings are in close dialogue. Both find inspiration in the other's work. What's more, they were friends. Resonances between Levinas's views on suffering and Blanchot's work on the disaster are not accidental.

to suffering's senselessness, or the possibility of meaningful suffering, comes into being in the interhuman space where suffering issues an ethical call for aid to the witness. "Interhuman space" entails more than a multiplicity of consciousnesses. It presupposes a "non-indifference to one another" (Levinas 1998, 100), a reciprocal altruism that expects no reciprocity, no return of favour. The interhuman space is "*my* responsibility for the other" (Levinas 1998, 101; emphasis in original). What this means: bearing witness to the other's suffering in an interhuman space issues forth a call for salvific efforts from the witness, one more powerful than a request for help. In its senselessness, the other's suffering is nothing but futile evil, and witnessing the proximate other's suffering demands nonreciprocal analgesia, salvation.

Levinas believes the only way suffering can be made meaningful is by taking on responsibility for the other's suffering – by suffering to soften the other's suffering. Beatrice's and Emma's suffering is salvific in and of itself, since it permits deeper communion with God. They need not suffer "for" another's suffering to be saved, because salvation is attained through the self-God relationship. This said, a significant portion of their suffering's meaningfulness derives from the sense of purpose they gain in caring for others in their community. As Beatrice and Emma convey, God makes them suffer individually so that they would help those who suffer like them. In Levinasian terms, one purpose of their personal suffering is to lighten the useless suffering of the other. In the case of sickle cell, altruistic commitment necessitates grappling with social forces they experience as sustaining their community's suffering. Beyond the self in its relation to God, then, suffering is irredeemable, purposeless.

Which brings me back to my ruminations on community. In the second chapter, I indicated the creation of empathic ties of intimacy and care between people of the community, who share an infinitude of suffering in its midst. Testimony, which makes up a large portion of sickle cell events, is reciprocal (Frank 1995). It is an act that places one's suffering within a community of fellow sufferers and thereby becomes an interpersonal opening onto witnessing others (Frank 1995). To share – testify and listen to – suffering with a community of fellow sufferers potentiates the development of empathic relations to listening others who possess intimate knowledge of one another's suffering. Thus, to share suffering awakens people to one another's proximate suffering, an awakening that cultivates reciprocal responsibility for the other. In this way, sharing suffering opens up an interhuman space, in a Levinasian sense – a space of reciprocal altruism.

Arising from empathic ties of relationality forged through the sharing of suffering is an impetus to care for the suffering other, to assume responsibility for their suffering, as Beatrice and Emma do, with no expectation of reciprocity. The empathic space opened up through the act of sharing suffering lifts suffering from its individual uselessness and into the interhuman realm, where suffering becomes meaningful in its call to others. Now, having glimpsed a corner of Beatrice's and Emma's interior worlds, we may catch sight of a vivid religious gleam to this altruistic impetus. I do not suggest faith is required for empathic intimacies to emerge through the sharing of suffering. Only that, in the community, faith interlaces those intimacies.

The community's participants care for one another. Through acts of care, they strive to erase their peers' suffering. They may share treatment and medication advice, help newcomers navigate the medical system, or lend ear to fellow patients during crises. Some, like Cam and Yves, devote incredible time and energy to alleviating their fellow sufferers' suffering by volunteering for Crescent. Others, like Aisha and Crescent's president, dedicate their lives to the cause. Sickle cell associations' very existence is testament to this widespread devotion to lightening fellow sufferers' suffering. For Beatrice and Emma, as well as other evangelicals whose voices are not heard in this chapter, an altruistic dedication to aiding fellow sufferers is inextricable from faith. While sickle cell sufferers may reach one another by sharing suffering, faith accomplishes something beyond sharing. It is a sinew holding together people of the community in a network of mutual care. In their reckoning, God has handed them suffering so they may come to him, yes, but also so they may "help others who are sick like [them]," like Beatrice said. *He has created me to give.* And so they give their own suffering to their suffering peers. They suffer to render their peers' suffering transitory.

In this manner, their individual suffering becomes salvific *to others*. They impart salvation from suffering on this living world, through caring for others in the community. Indeed, the sickle cell community is Beatrice's and Emma's life purpose: their sacrificial effort to assuage its shared suffering. The two are instances of "the just who suffers for others" (Levinas 1998, 241). The word community's original suffix – *munus* – denotes gift, Roberto Esposito (2009) reminds us. "It is the gift that one gives because one must give and because one cannot not give" (Esposito 2009, 5). Beyond commonalities, what binds together a community, Esposito says, is an obligatory gift. A perpetual debt to the community's fellow participants. In Levinasian lingo: an "inescapable obligation" (1998, 95) to tend to the other's suffering. The sickle cell community

lives on through the sharing of suffering, but it is sustained by many (not all, of course) of its participants' altruistic gifting of their own. Faith in God's goodness seems to bring forth evangelicals' consciousness of their inescapable obligation to their community's suffering peers, and thereby binds the community together. So does it propels the fights against antiblackness and sickle cell stigma.

The struggles against antiblackness and stigma are integral parts of their selfless duty to soften their peers' suffering. We should keep in mind, so Beatrice and Emma say, that God does not determine human action like a puppeteer. *God knows where he wants you to end up*, Beatrice said during our bedroom conversation. *It is up to you to follow his plan or deviate from it.* Humans are granted agency and, by analogy, the capacity to inflict harm. Theirs is a nudging God. He speaks to them, hints at certain actions and directions for them to follow. He does not, however, dictate their behaviour. Many choose not to heed God's plan. Failure to follow his plan will cause his disappointment, his sorrow, Emma and Beatrice tell me as we chat during the camping trip. But God does not control humans like mindless pawns on a chessboard. He knows where each piece should end, but lets the game play itself. In this way, Beatrice and Emma do not hold God to account for other people's actions.

I see it too, the flickering of the line parsing God's hand from human agency. It is not perfectly clear to what extent the individual suffering brought on by antiblackness and stigma is or is not part of God's trial of faith. Likewise, though Beatrice and Emma take concrete actions to soothe their peers' suffering, and insist on their capacities for independent reason, in some ways they are conduits for God's will. They walk the path he has traced for them, and paradoxically appear to find agency along their predefined paths. Yes, I see them too, the lingering theological inconsistencies and indeterminacies.[30] I recall Luhrmann (2012; 2020), who reminds us that faith is less about explaining reality than transforming it. People turn to faith not to make logical sense of the world but to cope, to gain a sense of purpose, to feel better than they would without it, to keep hope alive against the threat of despair, to feel loved when they feel

[30] The more I think about them – the harder I try to create coherence out of these theological debates – the greater my analytical anguish. I regret not pressing people further on these inconsistencies. Where does God's plan end? Why is your peers' suffering not individually salvific like yours? Is the individual suffering you experience from antiblackness and stigma part of God's plan for you? Did he foresee their entanglements with sickle cell? I did not ask these questions, because I only identified the paradoxes after finishing fieldwork. I can only try to create some sense based on my extrapolations. Although, my interlocutors did not seem very concerned about these paradoxes.

broken. Put another way, religion transforms the world of its followers into an essentially good one. People embrace it to fill the barrenness of suffering with meaning and purpose.

Beatrice on this: *I believe, and the more I believe, the more belief becomes a drug. I couldn't live with a void inside me*. She could not live without *feeling* God's presence in and around her, could not live with nothingness, senselessness, a life starved of purpose, bereft of ultimate goodness. God fills the void of suffering's senselessness within her – more so than provides a logical explanation for the world's evils and sufferings beyond her own. Faith is about intimacy, solace, experience, feeling. Faith *feels* like ice cream in the summer, as Beatrice puts it. She turns to faith to *feel* God's soothing presence, his comfort, the peace of God. And through faith, purpose may surge forth from the depths of suffering. She is reminded that the world is good, because *God is good.*

The evangelical faith, with its strong emphasis on predetermination, does not preface fatalistic attitudes to others' suffering. Never do the faithful I know justify their peers' suffering by recourse to God's plans for them. Their fellow sufferers' suffering is a plight. Nothing else (another theological aporia that seems to matter little in Beatrice's and Emma's lives, perhaps one that trickles from evangelism's abdication to divine unknowability). Trusting God renders possible departure from the senselessness of individual suffering. Walking this purposeful path leads to their suffering peers, who suffer uselessly from sickle cell, but also from its the entanglements with antiblackness and sickle cell stigmatization. To accomplish their life purpose, they must labour to render the timelessness of the wake transient. They must try to redress the violence of antiblackness and fight against antiblack racism's iron grip on medicine so that biomedical knowledge, which is God's knowledge, may shine the light of cure upon the world. They must spread awareness in their diasporic communities about their illness to wring the venom of sickle cell stigma from their culture, to dispel its association with witchcraft – at the cost of their own stigmatization. They must participate in blood drives, raise funds for innovative biomedical research, as well as volunteer for and donate to Crescent to help fellow sickle cell sufferers in need – newcomers most of all.

Spurred on by the noetic certainty that they do not suffer in vain, that their suffering is good, that their peers' suffering is indefensible, that they were created to gift their suffering to the sickle cell community, sufferers like Beatrice take on the mantle of worldly salvation in their fellows' illness-ridden lives. Not so they themselves may taste the sweet fruits of a life without

suffering, but so others might.[31] However redemptive their own suffering, others' is unforgiveable. Eternal, this truth brooks no argument. It is a truth that preserves the sickle cell community, a truth enabled by the sharing of suffering. If commonalities of experience permit the sharing of suffering by inclining people toward each other, in turn sharing suffering enables people of the community to bear witness to their peers' useless suffering. By kindling the sharing of suffering, the sickle cell community becomes a space cultivating reciprocal altruism. Being with fellow suffers – bearing witness to shared suffering – allows Beatrice and Emma to put their own suffering to service, so their companions' suffering will one day be over and gone. So they may not suffer so much in the meantime, by gradually releasing the world from antiblackness and sickle cell stigma, by smaller gestures of care.

Meaningful in them, useless in others: the sickle cell community.

[31] That faith helps them find meaning and purpose is not to say they are seeking martyrdom. They do not want greater suffering. For one, Beatrice and Emma attend events hosted by Crescent, simply to connect with their community. Thus, they do look to break isolation and lift some of their socially induced suffering. That they find salvation in their individual suffering does not mean they want to suffer alone, nor as much as possible. Simply that their dedication to the sickle cell community is not self-interested, and that their sacrificial acts of gifting suffering keep the community alive.

Conclusion

The shadow of death surrounds the sickle cell community in which I spend the swelter of 2024. In the wake of a young boy's passing from sickle cell, a bereaved father founded Crescent. His mission was, and remains, in his words, to "help others with the disease."

When I ask Crescent's president the question I presented Cam with – Why do they organize so many events for sickle cell families? – he answers that people need them. "People receive medical, but not psychological, care. It allows them to talk amongst themselves, because they are impacted by the disease on many levels. They need these kinds of events to share and exchange, to put their lives in common, and to understand others' realities. It allows them to break isolation and the feeling that they're the only ones in the world who live with the disease."

Patients are isolated here, said Cam. People of the community are profoundly isolated in multiple ways. They shoulder the weight of exile, that irremediable rupture from their loved ones and communities left behind in Africa or the Caribbean. They feel out of place in Canada's cold culture, yearn for the warmth of Africa. In North America, they suffer from the violent and tenacious afterlives of slavery, grown into the form of racialized healthcare inequities. Their illness – their pain and suffering – receives less attention and funding than other genetic diseases, not least of which cystic fibrosis. (*We are Black, so no one listens when we speak of our pain.*) Sickle cell patients are called drug seekers at the hospital and denied pain medication. They are Black in an antiblack world. And, so, they bury their kids and carry on, in Aisha's words, condemned to a life of grief unending.

But they are also marginalized, ostracized, silenced in their own culture. If Canada's dominant culture turns a deaf ear to their pain, their culture muffles their cries for help in other ways. Aisha: *Stigma is everywhere.* Stigma's venom courses through their tropical homelands, and has followed the trail of migration. It contaminates their diasporas in the Montreal and Ottawa regions and continues to cast people with sickle cell to the fringes of collective life. People of the sickle cell community, especially women, are excluded from social relations on which their livelihoods depend. Witchcraft beliefs intermingle with a cultural aversion to expressing suffering, hindering access to healthcare, and throwing patients and families into deeper isolation. Stigma percolates through their religious communities in their native and adoptive lands, entwining with theodicy. Many have suffered spurning judgment from

congregations for their illness. They have been told to pray sickle cell out, to exorcise it, that their illness is a manifestation of evil, of the devil, a retribution for sinful character, divine punishment for weakness of faith.

The story penned in this thesis speaks to the nonrecognition of the community's suffering, their social exclusion, their falling out of social life. In our antiblack world, they live their illness in the wake of transatlantic slavery. They understand that biomedicine and the social world in which it is embedded have historically dismissed the pain and suffering of their Black bodies, while also perpetrating harm. It continues to do so. Compounded with the stigmatization of sickle cell in their home communities, diasporas, and religious communities, sickle cell sufferers find themselves at the confluence of intersecting axes of social exclusion. They live illness as a condition of social abandonment, a living death tugging physical death ever closer. They suffer sickle cell in near silence, within the social hollow they have slid into.

Sickle cell's public invisibility is slowly lifting in Canada. In 2017, Canada became the first country to recognize a National Sickle Cell Awareness Day. In 2023, Senator Marie-Françoise Mégie, a physician of Haitian origins with decades-long ties to Crescent, introduced *Bill S-280: An Act respecting a national framework on sickle cell disease* to the Parliament of Canada. (I do not know whether she herself carries the trait.) Crescent and Aisha's association actively participated in the drafting process: Crescent's president, Aisha, and Cam, among others. The bill aims to secure sickle cell's place in the medical curriculum, increase research funding, bolster awareness campaigns, improve access to screening, and create a nation-wide registry. Rather curiously, many non-activist people I meet in the sickle cell community are unaware of the bill's existence. At best, they have heard of it vaguely. As for politically engaged Aisha, she bemoans the performative character of Canada's recognition of Sickle Cell Awareness Day ("You say June 19th is Sickle Cell Awareness Day, but what have you done after that?"), as well as the legislative stalling of Bill S-280. She worries the bill will, in her words, "die" before it is formally adopted, and confesses to "losing sleep over that." Lumbering but real political developments do not appear to impact the community's understanding and experience of sickle cell suffering as one of social abandonment.

Though it is, in Aisha's words, "surrounded by grief," the sickle cell community broaches a light in sickled lives. I picture the community as an oasis tucked away in the desolate landscape of exile its participants inhabit precariously. The community is acquainted with grief, it carries

many sorrows, but it is a therapeutic sanctuary, a refuge for healing their historically and culturally situated suffering. People of the sickle cell community incline toward each other by suffering in very similar ways. Their suffering alloys sickle cell with the afterlives of slavery, blackness, similar histories of migration, cultural stigma, and faith. In the community's midst, people exchange perspectives and experiences, share, "put their lives in common." The community is the only place where they belong because it is the only place where they are among people who understand the multilayered profundities of their suffering. Where they can communicate their suffering, resonate with people who share racial and cultural identity, as well as faith, without fear of stigmatization. Where they can hold vigil for losses in the community. In the sickle cell community, people find companionship and sanctuary and family, huddle around the cultural warmth of their lost homes, and mitigate the injuries of antiblackness and stigma. Simply being together is analgesic.

But the people of the community do not only exist with, but for, each other. They care about and for each other, deeply. Sharing suffering in its midst detaches it from its senselessness. In being voiced, the other's suffering is redeemed it from its remoteness, from its abstractness. Sharing suffering is an opening onto the suffering other, a call for aid and an altruistic response to it. Ties of empathy – responsibility for the suffering other – are woven in the interhuman space of the sickle cell community. Faith, the evangelical faith most of all, is inextricable from those empathies. The Holy Spirit pulsates through the sickle cell community. In a few ways, it is a salvific force in people's lives. People like Beatrice and Emma suffer, they suffer greatly, but do not suffer senselessly. Surrounded by God's embrace, they are never truly alone despite the layers of social exclusion that arise from sickle cell's entanglements with the social world. God delivers them from isolation, and from despair. For God is all- and ever-knowing, and he holds knowledge of cure. His curative benevolence promises to release it onto the earthly world in the imminent or distant future, through biomedical advances. Together, God and biomedicine keep hope alive in the sickle cell community.

God is patron of cure, but so is he purveyor of individual suffering. Yet no suffering of his is senseless. Beatrice knows her own suffering is purposeful. God's plan aims to lighten the world's suffering through Beatrice's actions. To this end, he has endowed her with the gift of self-sacrifice: she suffers to help others who suffer like her. Beatrice, as well as other evangelicals of the community, choose to walk down the path God has traced for them. His full

intentions are veiled to them, but they know their suffering must not go to waste. For suffering is meaningful in them, but useless in their fellow sufferers. Sharing suffering within the community kindles wakefulness to their peers' indefensible suffering. Witnesses must respond altruistically, must put their own God-given suffering to use. They become salvific forces upon their peers' lives, as they will labour until the end of the disaster of slavery, until the end of sickle cell stigma, until the end of scientific neglect, until the end of disease – the end of sickle cell suffering. It is faith, then, the sinew connecting it all together. Religious salvations of many sorts unfold in and through the sickle cell community. Salvation from suffering, salvation through suffering, the sickle cell community a convergence of both.

A silence has run alongside this extended conversation on suffering and salvation – and, so has it been said, silence is never an absence of sound but a limit of hearing, silence is a call for enquiry. Not once in the past one hundred pages is the prevention of suffering mentioned. Yet we do possess a direct means of saving future generations from sickle cell suffering. And how beguilingly simple it looks. Were sickle cell transmission to subside, sickle cell suffering would be preventable, and a cure less urgent. Individuals of sanguine character (and, it must be avowed, of eugenicist disposition) might even envision transmission coming to a full-stop a few generations down the road. Through concerted deployment of genetic screening, sickle cell disease is*,* genetically speaking, eradicable. With time, of course, and significant global coordination. However, the pragmatic simplicity of this solution is, quite like all pragmatism, a ruse. Even with vastly improved (but nonetheless wanting) access to sickle cell screening worldwide, global transmission rates are shooting up. By 2050, sickle cell births are expected to increase by a third, from eight to fourteen million (Piel et al. 2013). Population growth in the Caribbean and sub-Saharan Africa is behind the direful swelling, as it has been for the last decades (Piel et al. 2013). Note that the global sickle cell burden is growing at a faster pace than Piel and colleagues divined (Thompson et al. 2023). Projections bode ill.

In the sickle cell community I know, disease prevention is generally not regarded as the main path toward future salvation from sickle cell suffering. Of course, Crescent and its Ontario counterpart have advocated for universal newborn screening, and continue to encourage screening in Black communities. It goes without saying that dwindling transmission rates would attenuate their distress. But "the ultimate goal is the cure," Crescent's president tells me. He

himself does not dissuade trait-carrying sweethearts from bearing children. During two sickle cell events, I hear him promoting screening so that, in his words, "people can make enlightened choices." However, both times an amendment is added to the statement: it is not his intention to suggest trait carriers ought not start a family: "Forewarned is forearmed." Sickle cell treatment development, not disease prevention, animates most of the sickle cell community's advocacy and fundraising efforts. Sickle cell transmission is seldom addressed between community participants. If ever, really, save the two above interventions from Crescent's president.

People only, and rather reluctantly, speak on the matter after I have brought it up in private. Do you still want children despite potentially passing it down? (*yes, no, yes, I don't know*) But what about transmission? (*hedging, I really worry about that, hedging, I will love them anyway*) If you were to start over, would you still have had children knowing they would live with sickle cell? (*yes*, *no, yes, no, I wouldn't change the ones I have*) Why did you decide to have a second child after the first was born with sickle cell (or the trait)? (*hedging, it was an accident, hedging, when you are in love…*) Do you ever feel guilty for transmitting the disease? (*yes, no, I didn't know, yes, no, a small guilt*) My pointed queries occasion discernible discomfort. People appear reticent to externalize their thoughts. They stiffen. Their replies are clipped or vague. They avert their eyes. They sometimes seem not to know how to answer. When I raise the issue more than once with the same persons, answers change. It may be that I inadvertently crossed a line with my probes into matters of transmission.

I am in the dark as to why disease prevention does not garner greater concern in the sickle cell community. A few hypotheses arise, naturally. Maybe the people of the sickle cell community are in thrall to the intertwined curative imaginaries of biomedicine and Christianity. Maybe some sexuality-related taboo lurks beneath the confounding silence. Maybe the topic ignites or resurrects feelings of guilt they would rather strangle. Maybe they read my questions as presumptuous imputations of blame for perpetuating suffering. Maybe they are resigned to the powers of courtly love. I do encounter it a few times, this rhetoric that we cannot choose whom we fall for. That nothing can be done if two carriers succumb to love's folly. Reverence for love recurs among evangelicals most frequently. Christianity is a well-known exponent of monogamous bonds.

Maybe the wish to bear biological children is so strong as to trump apprehensions of disease inheritance. This guess would align with the rampant fears of permanent infertility surrounding

hydrea I notice in the community. Recall Aisha, from the introductory chapter: *As Black people, it's very important for us to reproduce. We believe we are born on this earth to have children.* Many in the sickle cell community seem greatly preoccupied – but not quite daunted – by the prospect of passing down sickle cell. Childlessness seems to inspire more profound dread than disease transmission. They want a family: "it's my biggest dream," Alice once tells me. One patient's beloved even refuses screening. He does not want his sickle cell status to impact their decision to have children. Yes, the two turtledoves know they gamble with fate. Should the man carry the trait, the couple's child *will* crawl out of the womb on an expedited path to the tomb.

It may also be that some people of the sickle cell community entrust disease transmission to God. As we know, God's will is a compelling explanation for suffering in the community. Recessive inheritance is a lottery, and God *is* the ultimate dispenser of individual suffering.[32] (Relatedly, abortion is unthinkable for the vast majority.) The answer could hide in a curious admixture of these speculations. Or in an unimagined elsewhere. I don't know, I don't know. All I know is that people of the sickle cell community do not regard the prevention of sickle cell births as their main path of escape from sickle cell suffering. As to why that is, I can offer no more than the above stumbling conjectures.

Despite the proliferation of black boxes across the thesis (the obscure workings of sickle cell stigma, unresolved theological paradoxes, and the charged silence surrounding disease transmission), a nugget of wisdom may be disinterred from the sickle cell community's story.[33] The reader can retrieve the lessons they wish from the story told, which might diverge from mine. In the end, text is independent from author, text defies closed message, text is as multiple as there are readers. With no ambition of argumentative persuasion, I simply share what I learned, in order to leave the reader with more possibility for thought. After all, sharing is at the core of the sickle cell community. It is equally the beating heart of the academic community.

[32] Which would raise anew the theological paradox of human agency versus predestination. So would my (very speculative) hypothesis about the exaltation of romantic love in the community. People of the sickle cell community make it clear that they possess agency in lifting their suffering. However, it would be worth asking whether the same sense of agency applies to the prevention of suffering. I sense a collective resignation to sickle cell's perpetuation. I may be mistaken. But if my impression turned out to be accurate, a more sustained interrogation of agency would be warranted.

[33] I owe the productively polysemous term "black box" to my advisor.

So if the story of the sickle cell community has been one of sharing, in the following I appeal to a shared humanity. Stubbornly, I cling to the hope that no interhuman alterity can ever be absolute. The universal may only ever be circumstantial, but it is not for that matter untrue. Does not the eternal truth of illness remind us that, at bottom, we are all just people? With this possibly naïve but steadfast conviction in suffering's relative universality, I bring to the page one flash of insight about human suffering I have gotten from the sickle cell community. It is theoretical and existential in equal measure.

The sickle cell community beckons me toward the realization that theories of social suffering and redemptive suffering are not antipathetic to each other. At first sight, the irreconcilability of these two views strikes one as self-evident. When suffering is categorized as social and experienced as a product of the social world, it dons the mantle of moral repugnance. Suffering is injurious, a plight that calls for remedial action, when it is conceptualized as a social problem – a consequence of human evil. Conversely, theologies of redemptive suffering, subsumed under the broader framework of religious providentialism, understand suffering by pointing to the hand of God. Providentialism hinges on a conviction in God's active involvement in human affairs. Theodicies of suffering attached to providentialism understand suffering alternatingly as punishment for sin, or a divine tool for humanity's redemption (Levinas 1998; Wilkinson & Kleinman 2016). Whether retributive or redemptive, providential suffering does not fuel moral repugnance as does social suffering. Suffering is but God's will made manifest.

Through occidental history, providentialism's wane and social suffering's wax have dovetailed each other. As Wilkinson and Kleinman (2016) describe, to experience misfortune as a product of the social world, as is the prevailing style of suffering in the West, is contemporary. Moral sentiments weaving this novel experiential configuration called social suffering broke surface as the previously dominant mode of suffering sank. Christian providentialism, or theologies of retributive and redemptive suffering, enjoyed popular currency until the seventeenth century. As suffering came to be interpreted through the lens of social suffering, providentialism faded as a coherent explanation for suffering. It is thus when the explanatory power of Christian providence quavered that a social understanding of suffering set in.[34]

[34] For an in-depth discussion of the Western history of suffering, see Wilkinson & Kleinman 2016. For a modern historicization of suffering, see Fassin & Gomme 2012.

Historically speaking, then, social and redemptive suffering seem to have cancelled each other. Not so in the sickle cell community.

Fieldwork has taught me that understandings (and experiences) of suffering as social and redemptive can collide and entwine. It has helped me to see that they can even be complementary, however messy their complementarity, rather than purely discordant. Social consciousness and awareness of divine providence hover together about the sickle cell community. People resort to both to understand their suffering. In accordance with the cultural salience of social suffering, especially the contemporary might of antiblack racism as a narrative of collective Black suffering, people of the community identify social forces as causes of sickle cell suffering. When they couch their experiences of suffering in the social world, sickle cell suffering is a plight that demands remedial action. Conversely, when they express those experiences through Christian theology, moral repugnance ebbs away.

As already explained, commitments to social and redemptive suffering appear to operate on different levels. Individual suffering can be redemptive (salvific), but the community's suffering inspires moral outrage and analgesic efforts. The distinction is imperfect. They know sickle cell stigma and antiblackness shape their individual suffering, but never clearly demarcate God-ordained individual suffering and socially inflicted individual suffering. This theological paradox remains unresolved for now. Nonetheless, oscillating recourse to providentialism and social suffering to conceptualize suffering carries, in my view, theoretical and existential freight.

Because a question wells up: why. Why are both present in people's understandings of suffering, despite their apparent discordance? I suspect they mediate each other's explanatory lapses and fill each other's existential lacunae. While social suffering explains collective suffering well, it seems to fall short of accounting for individual suffering. It answers the "why us?" question, but leaves unanswered the "why me?" question. On a collective level, people of the sickle cell community know that they suffer because they are Black in and antiblack world, and because their Afro-diasporic culture is hostile to sickle cell. But why me, and not my cousin? Why do *I* suffer so, while my sister, with whom I share genetic heritage and racial identity, is spared? Social suffering leaves individual suffering up to chance, when it comes to monogenetic diseases. Sickle cell inheritance is the luck of the draw.

Enter providentialism. Evangelical theology accounts for individual suffering. It unequivocally answers the "why me?" question. Why me? Because my God wishes it so,

because it is part of his unknowable plan. However, as I noted earlier, evangelical theology is plagued by partial explanatory reach. It tends to leave unexplained, or at least underexplained, large-scale suffering. Again: it promotes intimacy with God over theological analysis. Social suffering thus appears to fill theology's lapses, and vice-versa.[35] Hence their coexistence. By themselves, they afford insufficient explanations for suffering. Together, they cover the "why" dimension of illness in its full range: why us, why me. It therefore appears theories of social and redemptive suffering *can* be knotted together. Social suffering, in fact, reiterates not only deeply Christian values (altruism, compassion, justice), but also the biblical truth that God endowed humans with the capacity for reason and agency; and, by extension, the capacity to perpetrate good and evil. Social suffering, in this sense, finds accommodation in the Bible, despite its dissonance with a second Christian modality of suffering: redemptive suffering.[36] Socially perpetrated suffering ("our" suffering) is a plight, but divinely induced suffering ("my" suffering) is potentially redemptive. The line between "our" and "my" suffering blurs, of course. They are messy, the entanglements of social suffering and providentialism. But explanatory precision seems of lesser importance to them than what double recourse to social and redemptive suffering achieves in sickled lives, existentially speaking.

Theory is not without existential substance. The community's dual commitment to social and redemptive suffering affirms ancient wisdom about human suffering. There is no single way to suffer. No single way to bear our ills. The sickle cell community teaches me one of them, and I think its wisdom overflows sickle cell. Beatrice, Emma, Alice, Cam, Aisha, and their companions show me that explanations for suffering – their answers to the "why dimension" of illness – are not the telos of the existential questioning provoked by protracted suffering. The fundamental goal is to live, to live amidst a world gone ashen. Sickle cell sufferers push me to realize that, to beat on against the currents of great suffering, it is vital to hold on to our salvation

[35] In consideration of social suffering's cultural salience, perhaps it has become unthinkable to justify the other's suffering through providence, as Wilkinson and Kleinman (2016) argue.

[36] 17th-century theological developments propelled the rise of social suffering in European consciousness. In the wake of sectarian conflicts, the Latitudinarian movement promulgated a new reading of the Bible, one which promoted tolerance, compassion, and justice across Christian faiths. Wilkinson and Kleinman (2016) trace the genesis of what we now know as social suffering in part to Latitudinarian writings. That social suffering embeds in the Bible is, therefore, little coincidence. I wonder whether we might think of contemporary theories of social suffering as secularized Christian thought, and as displaying a form of secularized redemptive telos, thereby suturing the secular and the religious.

both from and through suffering. That is what bringing together theories of social and redemptive suffering affords the people of the sickle cell community.

The framework of social suffering provides sufferers agentic hope, a sense that human actions can help lift socially induced suffering. If humans can inflict suffering, so can they remedy it. People of the sickle cell community's tireless labour toward their community's salvation from suffering tells me that the hope of salvation does not, *cannot,* presume passiveness, or an absence of action. When suffering, and when witnessing others' suffering, we cannot sit back and await the coming of an externally imparted salvation, whether God's, biomedicine's, or a syncretic mixture of both. We must abide in the conviction that salvation from suffering is borne along the current of our worldly actions, that the horizon of darkness does not roll out until the end of times, that we have some power to halt its unfurling. It is hardly coincidental that the words patience and passivity descend from *pati,* a Latin word for suffering. Suffering is passivity, an undergoing. But suffering's constitutive passivity must not be allowed to spread to the second meaning of passivity: negation of agency. Inertia. We must have faith in our agentic capacities to bring about an end to suffering. Perhaps our own suffering, but most importantly that of our suffering fellows.

Agentic salvation from suffering, however, does not suffice. Most of all, we need to shelter from the loom of senselessness. From surrendering to the thought that our suffering is random, useless, a wasted ordeal. Irredeemable. This is salvation through suffering: purpose must be sought through a life replete with suffering. In Beatrice's words, life is not liveable within a void. It is the religious framework of redemptive suffering that helps my sickle cell companions break free from suffering's absurdness. No, faith is not required to redeem suffering through finding a sense of purpose. But in the sickle cell community, it is the path of escape from senselessness.

Fundamentally, people of the sickle cell community remind me that purposefulness is not to be pursued by turning inward, but outward, to the social or parasocial worlds we inhabit. In the long night of suffering, we cannot do without others, earthly or otherwise. We need the starlight of gods in the sky, the firelight of dwellers of the earth. We need interpersonal or spiritual proximity to others who understand, compassionate others with whom we may hold hands, others who avow suffering, who do not let it go unspoken. It is imperative that we not suffer in silence. That is the silence of the grave.

Having shared time with the community has imprinted upon me one last human truth: that to exist with others is to exist for others. To be with each other, to share lives, is to care about and for each other. Existence with and for others is where purpose is found through suffering, as it is among people of the sickle cell community. Existence with and for the gods, existence with and for our earthly fellows. For sickle cell, illness, suffering, life, cannot be borne alone. If it can be borne, it must be with and for others.

It is as Alice said. *We need to keep each other company.*

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