



MEDICAL

ANTHROPOLOGY

*Health, Inequality,
and Social Justice*

Fistula Politics

Birthing Injuries and the Quest for
Continence in Niger

Alison W. Heller



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MEDICAL ANTHROPOLOGY: HEALTH, INEQUALITY, AND SOCIAL JUSTICE

Series editor: Lenore Manderson

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for Continence in Niger

ALISON HELLER



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While so many relationships proved unreliable in the face of illness, my research revealed the steadfast and unwavering bond between mother and daughter. Women lucky enough to have their mothers were protected from the worst social consequences. They were advocated for and rarely alone.

This work is part of my story with my own mother. When her diagnosis came, days before I boarded my plane to Niger, she wouldn't let me stay. When her treatments failed, she wouldn't let me stop. She was a seeker of knowledge, a fighter for justice, and my strongest supporter. She, an immovable force, always at my side.

This is for her.

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FOREWORD

LENORE MANDERSON

Medical Anthropology: Health, Inequality, Social Justice is a new series from Rutgers University Press designed to capture the diversity of contemporary medical anthropological research and writing. The beauty of ethnography is its capacity, through storytelling, to make sense of suffering as a social experience and to set it in context. Central to our focus in this series on health, illness, and social justice, therefore, is the way in which social structures and ideologies shape the likelihood and impact of infections, injuries, bodily ruptures, and disease as well as chronic conditions and disability, treatment and care, and social repair and death.

The brief for this series is broad. The books are concerned with health and illness, healing practices, and access to care, but the authors illustrate too the importance of context—of geography, physical condition, service availability, and income. Health and illness are social facts; the circumstances of the maintenance and loss of health are always and everywhere shaped by structural, global, and local relations. Society, culture, economy, and political organization as much as ecology shape the variance of illness, disability, and disadvantage. But as medical anthropologists have long illustrated, the relationships of social context and health status are complex. In addressing these questions, the authors in this series showcase the theoretical sophistication, methodological rigor, and empirical richness of the field while expanding a map of illness and social and institutional life to illustrate the effects of material conditions and social meanings in troubling and surprising ways.

The books in the series move across social circumstances, health conditions, and geography, and their intersections and interactions to demonstrate how individuals, communities, and states manage assaults on well-being. The books reflect medical anthropology as a constantly changing field of scholarship, drawing on research diversely in residential and virtual communities, clinics, and laboratories, in emergency care and public health settings, with service providers, individual healers, and households, with social bodies, human bodies, and biologies. Medical anthropology once concentrated on systems of healing, particular diseases, and embodied experiences, but today the field has expanded to include environmental disaster and war, science, technology and faith, gender-based violence, and forced migration. Curiosity about the body and its vicissitudes remains a pivot for our work, but our concerns are with the location of bodies in social life and with how social structures, temporal imperatives, and shifting exigencies

shape life courses. This dynamic field reflects an ethics of the discipline to address these pressing issues of our time.

Globalization has contributed to and adds to the complexity of influences on health outcomes; it (re)produces social and economic relations that institutionalize poverty, unequal conditions of everyday life and work, and environments in which diseases increase or subside. Globalization patterns the movement and relations of peoples, technologies, and knowledge as well as programs and treatments; it shapes differences in health experience and outcomes across space; and it informs and amplifies inequalities at individual and country levels. Global forces and local inequalities compound and constantly load on individuals to impact on their physical and mental health, and on their households and communities. At the same time, as the subtitle of this series indicates, we are concerned with questions of social exclusion and inclusion, and social justice and repair—again both globally and in local settings. The books will challenge readers not only to reflect on sickness and suffering, deficit and despair, but also on resistance and restitution—on how people respond to injustices and evade the fault lines that might seem to predetermine life outcomes. Although not all the books take this direction, the aim is to widen the frame within which we conceptualize embodiment and suffering.

Alison Heller takes us to the heart of suffering. The setting is Niger, and, in particular, the four institutions in which women of all ages, married and single, with and without children, place their faith in the promises of doctors, donors, women's health advocates, and the media that their condition—the “sickness of leaking urine”—can readily be cured. Women with vaginal fistulas—holes from their vagina to their bladder or rectum from traumatic childbirth and poor obstetric care, which leak urine and feces—wait for months and years until their number comes up and a surgeon is on hand to effect repair. Many return for more surgeries; yet with each repeat surgery and further scar tissue, repair is less likely to occur. Others wait for surgery that turns out to be inappropriate: they may have recurrent bladder infections, or pelvic organ prolapse, or pelvic floor weakness, and do not, after all, have fistula.

Fistula Politics instantiates the embodiment of gender, certainly. But as Heller illustrates, familiar accounts of rejection and divorce, nasty co-wives and jealous in-laws, abandonment by kin, social exclusion, depression, and suicide overshadow other stories of women's resilience, pragmatism, and making do. Nigérien religious and kinship systems, gender, politics, and economics intersect to influence whether, when, and if women seek care when they are in labor, and from whom they receive care. These circumstances pattern women's risk of fistula, their experience of the condition, and their access to medical care.

Most of the women who end up in Niger's centers for fistula repair are desperately poor, rural women, who are often illiterate. Heller's interlocutors traveled

across the country, often at great personal risk, far from their husbands and kin, in search of a cure. In their absence from home, their husbands bring in co-wives, their families reconstitute, and their children grow up. Meanwhile, at the centers, women forge new ties, brought together by their faith and the everyday rituals of workshop, and by ethnic identity and language.

In this superbly illustrated book, drawing on her work with one hundred of the women who had chosen a pilgrimage of repair, Heller illustrates how popular narratives about fistula serve the interests of humanitarian organizations and their supporters, donors, surgeons, and the media, far more so than the interests and life chances of the women with fistula.

ABBREVIATIONS

AQIM	al-Qaeda in the Islamic Maghreb
CNRFO	Centre National de Reference des Fistules Obstétricales (National Reference Center for Obstetric Fistula)
CSL-Danja	Centre de Santé Léprologie de Danja (Danja Leprosy Health Center)
CSLF-Danja	Centre de Santé, Léprologie et Fistule (Danja Leprosy and Fistula Health Center)
DFC	Danja Fistula Center
DHS	Demographic and Health Surveys (Enquête Démographique et de Santé et à Indicateurs Multiples)
FGC	Female genital cutting
FGM	Female genital mutilation
Lamordé	National Hospital of Lamordé
NGO	nongovernmental organization
MMR	Maternal mortality ratio
RVF	Rectovaginal fistula
SIM	Serving in Mission (formally known as Soudan Interior Mission [since 1893], then Society for International Ministries [since 1980s])
UNFPA	United Nations Population Fund
VVF	Vesicovaginal fistula
WFF	Worldwide Fistula Fund

NOTE ON TERMINOLOGY

The condition: Obstetric fistula is a birthing injury caused by prolonged obstructed labor that results in chronic incontinence. Although *fistula* technically denotes any abnormal pathway in the body, throughout this book, I use the term as shorthand to denote obstetric fistula.

The place: The country officially titled the Republic of Niger, I refer simply to Niger. Its citizens are Nigériens (or Nigeriens), not to be confused with their neighbors to the south, Nigerians.

The women: To protect individual identities and respect confidentiality, I use pseudonyms for all of my interlocutors (and identify them by age and ethnicity). In some cases, I recognize that the use of pseudonyms is more for effect—to uphold a principle—than it is effective. In the two quotes from media pieces (where women’s real names are used by journalists), I substitute pseudonyms as a nod to women’s privacy while recognizing that their identities can still be easily uncovered through an internet search. I have considered this in my decisions regarding what to reveal and conceal.

FISTULA POLITICS



Portrait of a Fulani woman in Niamey, Niger

1 • INCONTINENCE AND INEQUALITIES

I came to know Fana, a 42-year-old Tuareg woman originally from Mali, at an obstetric fistula center in Niger's capital city, Niamey. Twenty-six years before we met, she had developed a birthing injury following complications during her first childbirth. Although the internal damage had been repaired seven years prior, the deep social, economic, and emotional scars continued to mark her everyday existence.

Fana was married at the age of 15 and soon after became pregnant. When her contractions began, she refused to acquiesce to the supplications of her family to deliver in the neighboring village's health center, its reputation tarnished by a string of recent maternal mortalities. Fana, who more than 25 years later remained just as stubborn, remembered how her resistance never wavered, even as her labor failed to progress for two days, then four, and finally seven full days. With each sunset, the quiet concern of her family swelled. Still, Fana reasoned that her chances of survival were better if she just stayed home.

After a full week of labor, Fana delivered a stillborn baby boy. Five days later, a persistent trickle of urine began to leak from her vagina. It did not stop for two decades.

Like many women who develop fistula, neither Fana nor her family had ever heard of the condition. Yet for the next 19 years much of Fana's life was dedicated to managing her incontinence and looking for treatment. Her quest for corporeal and social "normalcy" spanned five pregnancies, four husbands, three decades, two living and two stillborn children, one failed surgery, and—finally—a success: Fana was healed seven years before we met. But most women's pursuit of normalcy does not end with continence. Nor did Fana's. Long after the hole was sewn shut and the perpetual wetness had dried, her life was shaped by fistula and her tortuous quest for a cure.

Fana's story is one of economic deprivation, only exacerbated by the political turmoil in northern Mali, where the rise to power of the militant organization al-Qaeda in the Islamic Maghreb (AQIM) worsened her ill health and pushed her

to cross the border into Niger. Her experiences with fistula were shaped by conditions of poverty and structural violence. Fana's fistula was both caused by and resulted in poverty. Yet her story is also one of unlikely empowerment within a context of major constraints. Through necessity, Fana learned to advocate for her own health care, fight for the custody of her daughter Safi, and negotiate new rules with her latest husband and co-wife. Her story extends across decades, borders, and marriages. The causal connections are complicated. And contrary to many media and humanitarian portrayals of women suffering from fistula in sub-Saharan Africa, Fana is anything but passive. In the pages that follow, Fana's words, and the words of 99 other women with fistula in Niger, bring to life how this birthing injury is experienced, lived with, treated, hidden, resisted, capitalized upon, and integrated into everyday life.

In a world of one-percenters and the "bottom billion," where the space that separates people within and between countries is ever expanding, the consequences of inequality and the concentration of power pervade everyday life. Maternal health is a particularly powerful area for thinking about the winners and the losers of global exchanges and local connections. Global disparities in maternal mortality rates—that is, the deaths of women due to childbirth or pregnancy—between resource-rich countries and resource-poor countries are astonishing. They are among the largest of any vital indicator.

In sub-Saharan Africa, one in 36 women will eventually die from pregnancy-related complications. In the often overlooked West African country of Niger, the number is even higher. One in 23 Nigérien women will die from maternal causes. This begins to make sense in the low-level clinics of rural Niger: nurses and midwives may have purchased their degrees without hands-on training, and a practice called "abdominal expression"—physical force applied to the woman's abdomen by a practitioner's knees, elbows, or an external object during labor—is common. Poor access to often poor quality health services produces poor outcomes. To give some perspective, following the perilous route many West African migrants attempt every day to the north of Niger through the Sahara, across Libya and the Mediterranean Sea in Greece, the lifetime risk of maternal death for women is more than one thousand times lower: 1 in 23,700 (World Bank 2018).

Despite the high rates of maternal mortality, for every woman who dies from obstetric complications in Niger approximately 10 more suffer from severe acute maternal morbidity (Prual et al. 1998). These women experience severe complications in pregnancy, labor, or the postpartum period. Counted as "near misses," on the threshold of life and death, they survive—yet this survival comes at a cost. As a result of obstetric complications or poor management, an estimated 10 to 20 million women develop obstetric-related disabilities each year (Filippi et al. 2006). Some injuries are common; for instance, in the Gambia, nearly half (46 percent) of all reproductive-age women sustain pelvic damage from childbirth (Walraven

et al. 2001). And some of the injuries are uncommon but life altering, as is the case with obstetric fistula. Although hemorrhage, hypertensive disorders, and sepsis are all important contributors, obstructed labor—the cause of obstetric fistula—is the leading cause of maternal morbidity in Niger (Prual et al. 1998).

Fistula might be imagined as a physical manifestation of global inequity, local disempowerment, spatial precarity, and economic vulnerability. Although between 1 and 2 million women live with fistula in the Global South, predominantly in sub-Saharan Africa, it is nearly nonexistent in the Global North (Adler et al. 2013; Lewis, De Bernis, and WHO 2006). The last fistula hospital in the United States closed its doors over one hundred years ago, when biomedical obstetric care became widely accessible. And while globally anywhere from 6,000 to 100,000 women develop fistula each year, very few come from cities, in Africa or elsewhere.¹

Fistula is often referred to as a condition of poverty, but it is also a condition of rurality. No matter how destitute, a woman living in a city like Lagos, Abidjan, or Niamey is unlikely to labor at home for a week as Fana did before making her way across town to a hospital. Even a woman of relative means deep in the Sahelian grasslands cannot move a health center closer, improve the conditions of the roads, or ensure that a qualified practitioner equipped with necessary materials can be found when she eventually arrives.

Fistula can more accurately be called a condition of *regional* rather than *individual* poverty, although the two are tightly entangled. It is a consequence of power differentials between multiple actors at multiple scales, ranging from the local to the global—between, for example, husbands and wives, practitioners and patients, and multinational trade organizations and Nigérien government officials. Fistula results from vulnerabilities to global, regional, and household-level poverty, to gender inequalities, and to reproductive demands.

Relegated to far corners of the rural Global South, obstetric fistula has until recently been shrouded in relative obscurity. But an increase in international attention to the condition has spawned a proliferation of organizations and institutions focusing on fistula prevention and surgical repair across sub-Saharan Africa.² Fistula is no longer thought of as a lifelong condition of incontinence; biomedicine now offers hope for a full recovery. However, despite media and humanitarian accounts of fistula surgery as a relatively straightforward and highly effective intervention, for Nigérien women the pursuit of surgery often involves disappointment—long waits and frequent surgical failures. As a result, the lives of many women in Niger are transformed twice: once by a delivery gone awry, and again by the quest for continence, which can take them away from their families, husbands, and their social, productive, and reproductive lives for months, years, and sometimes decades. These absences are socially and emotionally (and sometimes financially) costly. Yet, despite the high price of treatment, women remain tethered to fistula centers by their hope for a cure and their faith in the

power of biomedicine. This often misplaced confidence in surgery's promise to reestablish bodily and social integrity is fueled by the clinics and their financial interests in holding women.

By engaging with the women whose lives have been transformed by the condition, in this book I read through fistula to illuminate many larger questions about power, biomedicine, stigma, resilience, care, kinship, commodification, and representation within the context of illness and treatment-seeking in sub-Saharan Africa. This exploration of the lives of women with fistula enables us to better understand how women whose agency is constrained—by rurality, age, ethnicity, poverty, and parity—navigate the West African health care systems that have been privatized and decentralized by half a century of neoliberal policies.

This book's title, *Fistula Politics*, reflects not only the fraught and contested struggle over limited resources and the power to define and diagnose that play out in the public health sector, but also alludes to the broader politics of gender, Islam, biomedicine, humanitarianism, and a postcolonial global order. Throughout this book, I explore the manifold competing and collaborative power dynamics that shape women's social worlds, expose them to stigma, and determine their access to and outcomes of care.

Countless stakeholders have something to gain or lose when working with women with fistula. Competing for limited pots of funding and fleeting public interest, international nonprofit organizations are invested in highly choreographed narrative control. Niger's underresourced, weak public health infrastructure depends on funding from these same multinational nonprofit organizations. Fistula surgeons and their staff gain international visibility, prestige, paychecks, and per diems through often exploitative and frequently harmful biomedical encounters from which women struggle to disengage.

But it is not just the biomedical and public health establishment that has a stake in fistula politics. Husbands fear fistula's implications for their wives' fertility and their own social status. For co-wives, fistula changes the balance of power in the endless competition over scarce emotional and material household resources. In-laws may see fistula as the point to cut and run from a failed investment. Local religious leaders grapple with questions of purity, piety, and obligation after reproductive failure. And, ultimately, fistula marks a bodily, social, and perceptual rupture for the women it affects, requiring their skillful navigation of their own corporeal boundaries while remaining both socially visible to those back home and ontologically recognizable to themselves. These multileveled patterns of cooperation and contest where a panoply of actors have a stake in fistula and its outcome determine Nigérien women's experiences, helping to explain their vulnerability to fistula and mediating their success or failure in treatment-seeking.

These intersecting macro and micro politics actively shape a woman's vulnerability to fistula stigma and her power to resist it. Fistula politics help us to understand whose interests are served by the application of fistula stigma, and how that

stigma manifests and transforms throughout a woman's life. When we understand the politics at play, we can ask whether surgically repaired bodies lead to repaired conceptions of self and ultimately repaired social relationships. How is social stigma negotiated in the face of illness and treatment-seeking? How does the stigma of fistula grow out of and illuminate attenuated structures of support? How do local networks of care expand or contract in times of illness? How can co-wives be both integral parts of and the greatest threats to women's conjugal health? How might treatment-seeking be paradoxically harmful, and how might that be a result of the media and humanitarian organizations that aim to help? These questions—how, why, and when women's identities are reconfigured following fistula—undergird this book.

REPRESENTATION

Fistula is a lens that allows us to better understand how distant forms of suffering are represented, commodified, and medicalized, and why this matters. Because fistula spares the whiter and wealthier bodies of urban women—it is a condition almost unimaginable in Western bodies—it has come to be seen in the Global North as an archaic disorder of “traditional” Africa, affecting poor, brown-bodied women in the “deepest” parts of the continent.³ Often conceptually coupled with female genital cutting (a spurious link), fistula has captured the imagination of the West, where damaged genitals become a synecdoche for the oppression of African women who are rendered invisible and silenced by culture and religion.

Recognizable representations of fistula and the women who suffer from it are most visible in Western media and humanitarian donor fistula narratives. Recall the story of Fana that opened this chapter: a narrative of frustration, hope, loss, resilience, and chronicity. In contrast, Jamila's story is similar to many popular and humanitarian portrayals of fistula's passive victims. In his *New York Times* editorial, “Where Young Women Find Healing and Hope,” Nicholas Kristof (2013) introduces Jamila as a patient at Niger's Danja Fistula Center, drawing from and reproducing the familiar narrative tropes of fistula:

DANJA NIGER—They straggle in by foot, donkey cart or bus: humiliated women and girls with their heads downcast, feeling ashamed and cursed, trailing stink and urine . . .

The first patient we met is [Jamila Garba]; with an impish smile, she still seems a child . . . Her family married her off at about 11 or 12 . . . She was not consulted but became the second wife of her own uncle.

A year later, she was pregnant . . . She suffered three days of obstructed labor . . . The baby was dead and she had suffered internal injuries including a hole, or fistula, between her bladder and vagina . . .

Jamila found herself shunned. Her husband ejected her from the house, and other villagers regarded her as unclean so that no one would eat food that she prepared or allow her to fetch water from the well when others were around . . . She endured several years of this ostracism . . .

A few months ago, Jamila heard about the Danja Fistula Center and showed up to see if someone could help. Dr. Steve Arrowsmith, a urologist from Michigan . . . operated on Jamila and repaired the damage . . .

Women who have suffered for years find hope here . . . They are courageous and indomitable, and now full of hope as well.

I knew Jamila. I met her in February 2013 while I was in Niger researching women with obstetric fistula, six months before Nicholas Kristof's visit to the Danja Fistula Center. This was not how I would have told her story. Kristof's take is an exemplar of how fistula is often presented by a global media—worst-case scenarios, lurid tales in which girls are victimized by African men: abused, neglected, broken, dismissed, and discarded. Tales in which brown-skinned girls must be saved, and Westerners—their goodwill, their dollars, their surgeons, and their scalpels—must save them. In these tales, through Western humanitarian efforts and technological solutions, women are transformed physically, emotionally, socially, and sometimes religiously.

Over long chats, leisurely meals, and in-depth interviews with Jamila at the Danja Fistula Center, I heard a multifaceted story highlighting her impressive resilience and her negotiation of constraints. Jamila was married when she was around 14 years old to an adopted son of her grandmother. He was young too, and in Niger family marriages are considered the best kind of matches. At the beginning of their marriage they were happy. They were in love. Jamila told me that although she was married, they waited years before consummating their marriage—as was custom for young brides in her village. And when she eventually got pregnant, they were joyous. But her labor went badly, and she was left with a fistula. Her husband did not divorce her, and he certainly did not throw her out. After all, she had grown up in her grandmother's house, where he lived as well—when she married, she changed rooms, not houses. His home was her home.

But his behavior changed, and his love faded. He began to ignore and neglect her. After a year, as is common in Niger he took another wife as permitted by Islam.⁴ He married again before he could afford to construct another hut for her, despite Islam's requirement that husbands provide for wives equally. No longer having a space of her own, Jamila packed up her few things and moved across the courtyard, returning to her grandmother's room.

Jamila was not married to her uncle, she had not been ejected from her home when she developed fistula, and biomedicine did not heal her. Although Kristof suggests that Jamila had begun her search for treatment only months before, during our long talks she explained that her quest for cure had begun years ago. When

I met her, she had already undergone six unsuccessful surgeries. When we last spoke, that number had climbed to eight, and there was little hope that she would go home dry.⁵

The attitude toward women with fistula displayed by Nicholas Kristof, who has referred to these women as “lepers of the 21st century,” “pariahs,” and “the most wretched people on this planet” (2009, 2016), suffuses Western media. For example, *The Guardian* also has portrayed women with fistula as the world’s “modern-day lepers,” and both CNN and al Jazeera have positioned fistula as “a fate worse than death” (Grant 2016; Munir 2014; Winsor 2013). In the discourse of donors, media, and some scholarly works, obstetric fistula is presented as profoundly stigmatizing, a condition that results in divorce by husbands, abandonment by kin, exile from communities, and high rates of depression and suicide.⁶ Often with good intentions—to bring attention and resources to a previously invisible population of women—donor agencies and the global media generate and circulate a narrative of an iconic sufferer: young, stigmatized, and redeemable through surgical intervention. However, during the many months I spent in Niger with women with fistula, I found few archetypal stories of suffering or sufferers. Rather, I discovered impressive accounts of women’s resourcefulness, resilience, and agency as well as great variability in their clinical encounters.

The monolithic narrative of fistula, crafted at a distance in the newsrooms of New York and the offices of nongovernmental organizations (NGOs) in Washington, D.C., offers a compelling account of how women are devastated by the condition. The humanitarian and media industries have been deeply influential in how fistula care is envisioned and provisioned, but paradoxically often in ways that are counterproductive for the women’s goal of returning to their prefistula conjugal and social lives. Critiquing humanitarianism or the media is not a goal in or of itself of this work, both because I agree with their good intentions—to better the lives of millions of women—and because it is neither conceptually novel nor practically useful. However, carefully tracking how good intentions combine with long-standing colonial preconceptions offers not only a powerful counternarrative for social marginalization but hope for its reduction. Critical examination of the humanitarian and media fistula narrative offers some insight into why, even when healed, fistula continued to mark Fana’s everyday life and why Jamila was still waiting for her ninth surgery.

The stories of women like Fana and Jamila open up the lived realities and the social construction of obstetric fistula, neither of which can be examined without the other. The realities of treatment-seeking are influenced by the humanitarian and media formulations of fistula, which become reified social facts that are imbricated with clinical practice and everyday life. The critique of these narratives is thus instrumental, as it shapes available avenues of care, social perceptions, and embodied experiences.

"BROKEN VAGINAS" AND THE SICKNESS OF URINE

Seven years before I came to know her, Satima lay unconscious in her brother's arms. He carried her into the small emergency and triage room at Maternité Issaka Gabozy—Niger's top reference hospital for obstetric complications. Satima's labor had begun six days before in a rural village approximately 450 kilometers north-east of Niamey, which had no access to quality emergency obstetric care. Her labor did not progress normally, and when she was wheeled into the operation block for an emergency cesarean section, she was no longer conscious. Although Satima survived, her child did not, and her body was permanently marked by the struggle. When she finally awoke in the maternity ward, she found herself in a shallow pool of her own urine. She had developed what is referred to locally in Hausa as *ciwon yoyo fitsare*, the sickness of leaking urine.

Obstetric fistula results from prolonged and obstructed labor whereby protracted pressure of the fetal head against the vagina, bladder, or rectum damages soft tissue, starving it of blood and eventually producing pressure necrosis. If this process is not interrupted by delivery, which in the case of obstructed labor usually requires biomedical intervention such as cesarean or forceps delivery, the labor (and the resultant pressure) can last several days.⁷ In around 90 percent of cases, the fetus does not survive (Ahmed and Holtz 2007; Delamou et al. 2016; Wall 2012). The ischemic tissues die, and depending on how the fetal head was positioned during the labor, an abnormal pathway between the vagina and bladder (vesicovaginal fistula) and/or vagina and rectum (rectovaginal fistula) is produced. The result is persistent incontinence of urine and/or feces through the vagina.⁸ Fistula severity and symptoms can vary dramatically, as can the effects on a woman's psychosocial and physical health.

It is useful to think of fistula as the result of a "field injury" to a broad area, or as part of the "obstructed labor injury complex" as described by Arrowsmith, Hamlin, and Wall (1996). Fistulas are complex, and they are regularly accompanied by multiple birth-related urologic, gynecologic, gastrointestinal, musculoskeletal, neurological, or dermatological injuries. Women with fistula may suffer from perineal nerve damage (causing leg weakness and foot drop), stress incontinence, vaginal scarring, secondary infertility, renal failure, tissue loss, urethral loss, cervical destruction, amenorrhea, or pelvic inflammatory disease, among other problems. Women often arrive to fistula centers unable to walk due to nerve damage. Some have persistent infections, excoriated thighs, and constant pain. Others have undergone emergency hysterectomies, although they often do not know it. Women arrive consumed with anxiety—their bodies leak, and they are immobile, infertile, or inelastic. Fistula may be only one of their many health concerns.

Although fistula can cause long-term problems with physical health, including local infections, skin conditions, and kidney damage from attempts to manage

the condition by limiting fluid intake, a woman with fistula can, after an initial period of recovery from her traumatic labor, live a long and largely healthy life. Thus, the consequences of chronic fistula are often considered predominantly social and emotional: social isolation, marital disruption, and worsening poverty, anxiety, and depression may all be associated with fistula in addition to the related health problems (see Ahmed and Holtz 2007; Barageine et al. 2015; Lavender et al. 2016; Mselle and Kohi 2015; Wall 2012; Yeakey et al. 2009). But these outcomes can vary dramatically depending on the individual woman, her social context, and her treatment-seeking experience.

Small, fresh fistulas are sometimes closed with catheterization alone, but surgical intervention is the most effective treatment. Under ideal conditions, first-time operations on women with small fistulas that do not involve the bladder base or urethra offer women the best chance of success. However, after undergoing catastrophic labors, most women in Niger do not have straightforward injuries. Some 65 to 80 percent of Nigérien cases are “complex” and thus difficult to repair (Cam et al. 2010; Falandry 2000; Karateke et al. 2010). Fistula surgeries frequently fail. Even when they “succeed,” they do not necessarily restore continence; in some women the hole may be closed, but the leaking persists. Repaired injuries often break down; after the first operation scarring accumulates, delicate tissues harden, and repeated repairs become less and less likely to succeed (Wall 2006). Yet women in Niger were rarely counseled about the likelihood of surgical success or failure. When catheters are removed after surgeries and urine begins to pool, surgeons and nurses usually tell women to be patient and to wait for another operation. There is no agreed-upon standard by which women may be categorized as “incurable” or “inoperable”; many women who have undergone double-digit surgeries, with almost no chance of repair, cling to hope at the fistula centers. The surgical backlogs grow as these women pass their days and months waiting for operations that rarely materialize and that seem doomed to fail.

DUSTY SKIES AND UNCERTAIN HORIZONS

Niger is the largest country in West Africa; occupying about 1.3 million square kilometers, it is the combined size of France, Spain, Portugal, and Belgium (figure 1). Yet few people—particularly North Americans—have heard of it. It is regularly mistaken for Nigeria. Microsoft Word programs do not even recognize its people, “Nigériens” or “Nigeriens” (pronounced *nē-ˈzher-ē-ən*, as distinct from their southern neighbors—*nī-ˈjir-ē-ən*) in its dictionaries. Niger’s invisibility confers the risk of ill-fitting parallels to better known, but very different, African contexts.

The experience of fistula in Niger is often mapped onto the experience of fistula in better-studied countries such as Ethiopia, home of the celebrated, long-established, and well-funded Hamlin Fistula Hospitals. Anita Hannig’s ethnography on fistula (2017) in largely Orthodox Christian Ethiopia highlights some

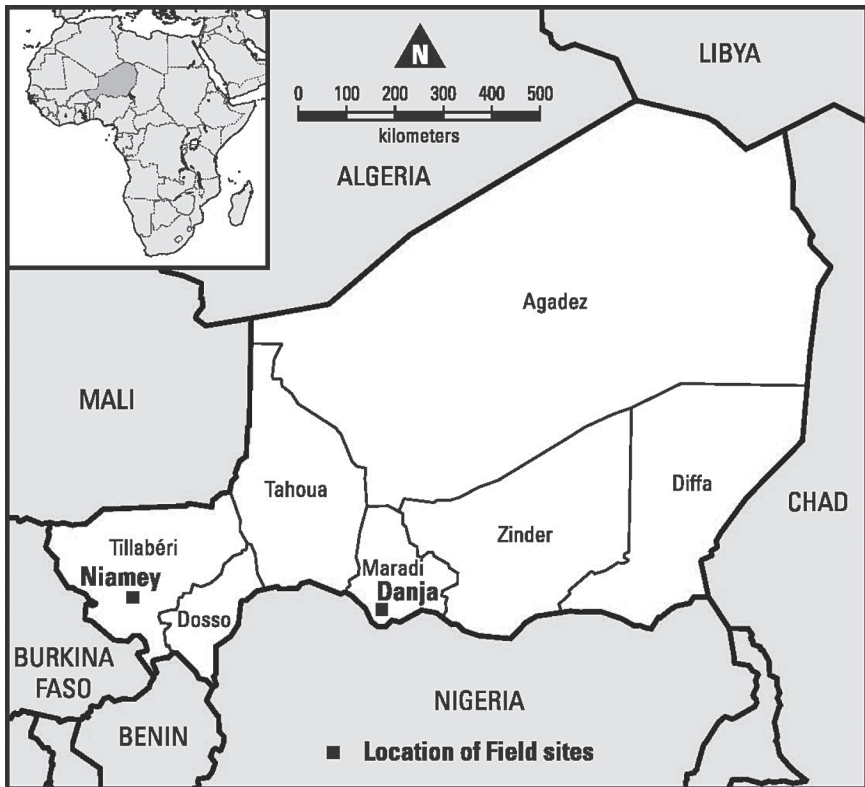


FIGURE 1. Map of Niger and its eight regions, with the Niamey and Danja field sites indicated (map by Eureka Cartography)

of these differences. For example, among Christians in Ethiopia, who practice monogamy, women with fistula are commonly divorced after the onset of their incontinence. In polygynous Islamic Niger, husbands are more likely to add another wife than to subtract one. These sustained, but drastically transformed, marital relationships result in very different lived realities of the same condition.

The process of treatment-seeking in Niger also has little in common with that in Ethiopia. At the Hamlin Fistula Hospitals, admittance, triage, physiotherapy, hospital life, and surgical intervention are streamlined, efficient, active, and promise good chances for successful outcomes (Hannig 2017). In the Bahir Dar fistula center in northwestern Ethiopia, Hannig (2017) found that a woman's entire stay, from admittance to release, averaged only 18 days, significantly less than the 32-day average in the fistula center in Ethiopia's capital. During their time at Ethiopian centers, women's daily schedules are highly structured; they are seen by practitioners, attend courses, and watch educational films. In contrast, the women at the fistula centers in Niger had, at the time I met them, already been waiting almost six months (an average of 180 days—10 times longer than in Ethiopia); their

waiting times ranged from two weeks to six years, and some had already undergone up to 11 failed surgeries. After we first met, most of these women continued to wait, and many were still waiting at centers for operations when I left Niger at the end of 2013.

Ethiopia's fistula hospitals teem with outside researchers and visiting surgeons, internal audits, and media coverage. By contrast, the fistula centers in Niger, particularly in the capital city Niamey, were often places of marked inactivity, with few if any staff on duty and remarkably little medical care, where women filled their days with waiting. This opacity of management can breed inefficiency, invisibility, and corruption. I make this comparison between Ethiopia and Niger to highlight the fact that illness and treatment-seeking are highly context dependent. Women's experiences and narratives of fistula in Niger—an Islamic, polygynous, poor country with insufficient health infrastructure—are unique.

Niger became independent from France in 1960, but its transition from colonialism to democracy was challenging. Over the years since independence, the landlocked Sahelian nation of 20.7 million people has grappled with single-party authoritarianism, Tuareg insurgencies, and military coups (Idrissa and Decalo 2012). Presently Niger contends with concurrent natural disasters of droughts, desertification, and floods; increasing threats of terrorism and violence along the border regions of Mali, Nigeria, and Libya; and a fertility rate that effectively doubles the population every 20 years. Given these barriers to peace and prosperity, Niger's economic struggles are unsurprising.

Niger does have vast wealth in natural resources—it holds the fifth largest deposits of uranium in the world. Uranium revenues led to a period of relative affluence in the mid-1970s, but by the early 1980s a profusion of petroleum in the global market and a decline in uranium demand due to the antinuclear movement led to the uranium market's collapse; Niger's brief era of prosperity came to a sudden end. The nation's borrowing continued, and debt amassed. After the bust of the uranium boom, Niger could no longer support its newly expanded bureaucratic sector and fell into bankruptcy. Structural adjustment programs designed and implemented by the World Bank and International Monetary Fund (IMF) were intended to radically cut government expenditures, decentralize service provision, transfer costs from the state to citizens, and minimize the role of the state to address economic crises; in countries such as Niger, the former structures were viewed as both overly interventionist and inefficient.

The neoliberal policies of austerity, structural adjustment, and increasing marketization that affected so many African countries in the 1990s resulted in years of unpaid salaries, shrinking public services, decreased wages and educational scholarships, pervasive corruption, and increased dependence on external aid. Investment in the health and education sectors slowed—few health centers were built, and few students were trained to eventually provide quality care within the remaining clinics' crumbling walls. In 1994, the local currency was devalued by

50 percent, catalyzing political instability and accelerating the decline into poverty for most Nigériens. In 1995, as part of a larger neoliberal movement in cost recovery, Niger's Ministry of Health followed guidelines set by the Bamako Initiative and instituted user fees in their health systems, resulting in a 30 to 40 percent reduction in consultations (Ridde 2015). In the absence of qualified practitioners or accessible public health centers, rural Nigériens were forced to rely heavily on unpaid village health workers and the intermittent care provided by charities and Christian missionaries.

Although the policies of structural adjustment have since fallen out of favor, the harm they caused has been long-lasting; since the 1990s, Niger's economy has seen little improvement, and most economic sectors have remained at a virtual standstill. By 2016, almost half the population lived on less than US\$2 a day, and the country's gross national income was among the world's lowest (World Bank 2018). Outside of the subsistence agriculture and animal husbandry on which the majority of Nigériens rely, the people's economic prospects are extremely limited. Many are involved in small-scale trading, transport, and informal markets; the few formal sector jobs has discouraged formalized education. As a result, Niger has the lowest rate of youth literacy in the world, at only 24 percent; the rate is lower still among adult women at 9 percent (World Bank 2018). Due to the low levels of secondary education, Niger has been unable to train enough qualified health care workers to meet its growing demands.

With few economic or educational opportunities, many Nigériens have redoubled their religious practice, finding moral purpose through religion.⁹ Piety in practice is not only a reflection of deeply held religious conviction, but also a means to demonstrate power, status, and wealth (or *arziki*, prosperity and well-being) when other means to do so are limited. In Niger, religious practice, modernity, and aesthetics are tightly entwined. Women with some money often invest in woven prayer mats, multiple strings of shiny prayer beads, and the Arab-inspired *abaya*—black robes set in stark relief to the colorful local garments.

Along with elaborately embroidered robes and traditional prayer beads, female staff at the Niamey fistula centers often wore tally counters on their hands, reminding me of the mechanical hand-clickers used by the school bus drivers and librarians of my childhood. Serving both as a visible display of moral worth and a fashion statement, these pedometers of prayer reflected the deeply material and highly performative side of piety (and social class) in Niger. But poor, rural women can enact piety only in the ways available to them: visible prayer, modesty, and increasingly conservative dress.¹⁰

Religion in the context of weak governmental institutions and few employment options has also led to a growing threat of radicalization. Affiliates linked to al-Qaeda in the Islamic Maghreb (AQIM) and the Islamic State (ISIS) pledged group Boko Haram are active in Niger, and they have become increasing threats

to the population and the country's stability. Although these groups are largely held in contempt by the majority of Nigériens, in an era of globalized Islam, what it means to be Muslim is being actively contested and redefined.

Such environmental, historical, political, and economic precarity has resulted in regularly dismal evaluations by the United Nations. As Claire Wendland reminds us, "Health indicators, like poverty statistics, tend to be most uncertain where life (and record keeping) is most precarious" (2012, 111). So, it is with care and a critical eye that we place Niger in a decontextualized global competition to be rated, ordered, and otherwise classified. Still, when considered with a healthy dose of skepticism, these numbers do indicate that lives of contemporary Nigériens are defined by widespread insecurity.

Niger is ranked last on the United Nations Human Development Index and is considered the least developed country in the world (United Nations Development Programme 2014). It also has the world's highest total fertility rate, 7.6 births per woman, which far surpasses the second highest, Somalia, which has 6.5 births per woman (DHS Program 2018).¹¹ This confluence of extreme poverty and population-level pronatalism leaves Nigérien women particularly vulnerable to poor maternal outcomes. The maternal mortality ratio (MMR), defined as the number of deaths due to pregnancy, childbirth, or postpartum complications per 100,000 live births, is often used as a proxy for the general quality of a country's health care system. The MMR for Niger was estimated by the World Bank in 2015 as 553 per 100,000. This was a marked improvement over 2005, when the MMR was measured at 760, and 2000 when it was 850, though these numbers, like all figures regarding women's obstetric health in Niger, should be viewed with some skepticism (see Wendland 2016).

Niger is also said to have one of the highest rates of obstetric fistula in the world. Given that the incidence and prevalence numbers for fistula in Niger are not definitive (the data are often the result of opaque methodologies and guesstimates), Johns Hopkins epidemiologist Saifuddin Ahmed has estimated the incidence to be between 700 and 800 new cases a year (Ahmed and Genadry 2013). At their current capacity, Niger's fistula centers only operate on a combined total of 500 to 600 cases a year. Ahmed estimates that if all 500 to 600 currently performed operations were successful (unlikely), and if no more fistula patients arrived at the centers (even more unlikely), it would take more than 26 years to clear Niger's backlog of current fistula patients.

GATHERING DATA

I conducted ethnographic research in three urban fistula centers in Niger's capital, Niamey, and one rural fistula center outside of Maradi (see figure 1). I spent the year 2013 and the summers of 2010 and 2014 in Niger. I observed 100 women

with fistula from six ethnic groups over time. I also spent time with and interviewed nine family members and five husbands of women with fistula as well as 23 fistula experts.

I adopted a mixed-methods approach to data collection to address gaps in the existing fistula research—specifically, the lack of women’s voices regarding their experiences of the condition and the treatment process, the absence of studies engaged with women over the long term, and the need for studies that integrate both qualitative and quantitative methods. I worked with these hundred women to gather data including their demographic profile, reproductive history, life events leading up to fistula, subjective experiences of living with fistula, internal and external fistula-related stigma, ruptures in social relationships, experiences seeking treatment, and perisurgical and postsurgical experiences (specifically social, economic, and emotional changes). To do this, I triangulated, using in-depth interviews, participant observation, and structured surveys. All the interviews were conducted in Hausa or French (both of which I speak) or Zarma (which I do not speak—I relied on my research assistants for translation). The Tuareg, Fulani, Kanuri, and Mossinke women who were also included in the research were multilingual, so I was able to interview them and chat informally in either Hausa or Zarma.

I conducted participant observation in the clinics and the women’s home villages during all phases of this research project. The observational data enriched and often contradicted what the interlocutors said during interviews and surveys. Because these contradictions reveal life’s messiness, particularly in regard to the subjects that cause us the most pain—such as crumbling relationships, bodily shame, reproductive failures, and futures of uncertainty—an approach of triangulation was integral to understanding the nuanced manifestations of fistula’s lived experience. I spoke with women. I watched them. I talked with their families and husbands. I read their charts (when I was granted their permission to do so). I administered surveys. Then I interviewed them again.

When interviewed three times over the course of a year, a woman might respond first that she is married, then divorced, and finally conclude, “I really don’t know.” Her chart might document her conjugal state as married, while her mother might assert that she is certainly divorced. Although this lack of cohesion presents challenges for quantification, it reveals the fluidity of experience, the women’s uncertainty about the future, and the care they exhibited in their self-representation. These ambiguities themselves are essential data about the discontinuities, ruptures, and anxieties at the heart of living with and seeking treatment for obstetric fistula. Understanding the lived experience of fistula is highly interpretive work, requiring a certain amount of translation, deduction, and even supposition and guesstimation.¹²



FIGURE 2. On a main thoroughfare in Niamey, donkey carts sharing the road with SUVs, taxis, motorcycles, and luxury vehicles

Niamey

Niger's capital city of Niamey is relatively tranquil compared to other West African capitals, which seem to vibrate with the constant motion of too many taxis on too few roads (figure 2). In Niamey, men congregate on benches and prayer mats, drinking strong tea under acacia trees. Commuters on bicycles pass by boys on overburdened donkey carts; in turn, the carts are passed by foreigners and Nigérien elite in white Land Rovers, the quintessential symbol of Western aid organizations. Camels advertise the newest cell phone or internet promotion as they languidly traverse the city—ambulatory billboards, branded without the least bit of irony.

Compared with other cities in Niger, Niamey is relatively liberal and westernized. Women weave through the city on motorcycles. Some do not veil or cover their hair, although most do. Conference rooms are evenly populated with tailored Western suits and *boubous*, local garments with flowing tops made of waxed *bazin* (hand-dyed polished cotton). Like many large cities of the Global South, in Niamey parallel worlds exist side by side. On the city's busiest roads, pack animals burdened with towering stacks of firewood share lanes with hulking military caravans. Girls in floor-length *hijabai* (tailored veils) with elaborate patterns of facial scarification share sodas with young women whose uncovered hair and

heavy makeup compliments Western-style, Chinese-produced jeans and blouses. Hausa and Kanuri peoples from the central and eastern regions, Zarma from the west, Tuareg from the north, and Fulani from throughout the country come together here, settling in ethnically homogenous neighborhoods but sharing work, economic hardships, prayers, and opportunities.

Yet, unlike many other large African cities, these synchronous realities feel somehow convergent. Conspicuous forms of wealth are rare in Niamey, and skyscrapers, freeways, and lavish shopping centers do not exist. This impression of a kind of flattening of economic inequality is borne out by the numbers. The Gini coefficient, which measures income distribution (and thus inequality) within a nation, ranges from 0 (perfect equality) to 1.0 (maximal inequality). In Niger, the Gini coefficient is 0.34—among Africa's lowest. For comparison, the continent's greatest inequality is found in South Africa, which has a Gini coefficient of 0.63; the United States has a Gini coefficient of 0.41 (World Bank 2018). In the world's least developed country, most everyone seems to struggle.

Most of my research was conducted in Niamey at three fistula centers. The first two centers, *l'Hôpital National de Lamordé* (National Hospital of Lamordé) and the *Centre National de Référence des Fistules Obstétricales* or CNRFO (National Reference Center for Obstetric Fistula), were operated by the Nigérien state as one semi-integrated unit. Located in the Sonuci neighborhood of Niamey, along the Tillabéri road, the CNRFO received both simple cases and referrals for complex fistulas from across Niger. My third Niamey research site, located just across the street from CNRFO, was run by the NGO *Dimol-Niger*. The organization Dimol was one of the first NGOs in Niger to become involved in fistula prevention, treatment, and reintegration work. However, when I was there, the organization had lost its capacity to provide surgical interventions, and it served only as a kind of hostel for women with fistula. Many women who spent months at the center, as we will see, did not know that they would never be operated on at Dimol.

Although the Niamey centers attracted women from all over the country (and sometimes from beyond Niger's borders), the women at the centers usually spent their time in ethnically homogenous "neighborhoods" on center grounds. In the Tuareg districts, light-skinned women lounged under makeshift tents of fabric, tree branches, and cinder blocks. More comfortable outside, the women braided each other's hair, wove baskets, constructed leather bags, and chatted in Tamasheq. Also clustered outdoors, napping, chatting, or praying, the Fulani women were easily recognizable: brightly colored fabrics, intricately beaded jewelry, "whiskered" patterns of facial scarification, tattooed bottom lips, and distinctively braided hair. In the Hausa *zongo* (a term used for settlements across West Africa populated by Hausa-speaking immigrants), Hausaphone women typically crowded together indoors or on shaded patios, reading from a Qur'an, listening to static-wrapped clips of music or sermons from a Nokia phone, or resting under a rare working fan. The rest of the indoor space belonged to the

Zarma women, who had demographic dominance in Niamey and within the centers (although not within Niger as a whole). With sufficient numbers, the Zarma women often subdivided themselves based on age.

Although these three centers in the country's capital were tucked into typical urban neighborhoods, the lives of the largely rural patient population of women at Niamey centers were not particularly urban. Women rarely left the centers' suburban confines or even the centers themselves, as most women had no money to spend, nowhere to go, and no one to take them there. Despite the promise and excitement of life in the capital, for rural women lacking money, know-how, and male protection, city life was unexplorable, so it was left largely unexplored.

Danja, Maradi State

I landed in Niger for my year of research in January 2013, on the day that French forces intervened in the neighboring country of Mali to fight groups affiliated with al-Qaeda in the Islamic Maghreb (AQIM), who had taken over the northern regions. Instability and fear spilled across the border. Due to a string of recent events—prison breaks, kidnappings, terrorist threats, suicide bombings—and growing instability in the south from Nigeria's terrorist organization Boko Haram, the Nigérien government restricted the movement of Westerners. At the beginning of my research, Westerners reportedly could no longer leave the capital without military escorts or U.S. embassy approval (although reports conflicted). Despite the warnings about volatile neighbors and travel restrictions, I spent a total of five months in the rural town of Danja, 700 kilometers east of the capital.

To skirt the overland travel restrictions, in February 2013 I took a United Nations Humanitarian Air Service flight to Niger's third largest city (a step up from my usual ride: a three-seater missionary bush plane that shook, hummed, and flew too low to the ground for my comfort). Maradi is often considered the country's economic and religious capital. Of its 175,000 people, the majority are ethnically Hausa, although it also has large ethnic Fulani and Kanuri minority populations. Maradi is around an hour's drive from Niger's very porous border with Nigeria, and money, commerce, people, and religious conservatism flow in from the south.

Fifteen kilometers south of Maradi, and 30 kilometers north of the Nigerian border (70 kilometers from the Nigerian metropolis of Katsina) is the *Centre de Santé, Leprologie et de Fistule Danja* (Danja Center for Health, Leprosy, and Fistula, or CSLF-Danja). Established in the 1950s as the Centre de Santé Léprologie de Danja (Danja Leprosy Health Center) by SIM (Serving In Mission, formally Soudan Interior Mission), the hospital originally operated as a mission hospital for leprosy patients.¹³ SIM converted long-term leprosy patients to Christianity; the patients then settled and built lives and families in Danja village, two kilometers from the hospital, establishing a small pocket of practicing Christians (Cooper 2006).¹⁴ The hospital eventually expanded to offer health services beyond leprosy care.

In 2012, a new set of buildings housing the Danja Fistula and Training Center officially opened on the hospital campus. The center was run by Worldwide Fistula Fund, an international secular nonprofit based in Illinois, in cooperation with SIM. Here, women could receive free repair surgeries, postoperative care, and a suite of capacity- and skill-building classes. To house the women through the sometimes very lengthy process of care (which can include months of waiting, recuperation, rehabilitation, and sometimes additional surgeries), women stayed in “the village,” six small houses built behind the hospital. Because fistula occurs largely in rural populations with very little economic capital, most women had spent two or more days traveling to the clinic. Many had left their homes on foot, walking for several hours before reaching a place where mule carts or taxis could be found. None spoke French, Niger’s official language. The vast majority were decorated with elaborate patterns of facial scarification marking their ethnic and regional provenance.¹⁵

Although the providers of care at the Danja Fistula Center were largely Christian, the patient population was not; nearly all women were faithful adherents of Islam. But in intimate spaces, strict practices of piety loosen. I spent much time with women behind the mud walls of compounds, shielded from the male gaze and protected from strict norms of coverage, silence, and invisibility. Behind the bricks, women spoke unguardedly of the intimate details of their bodies, their marriages, and their sexual lives. Although Maradi is known as the heart of religious conservatism in Niger, a stronghold of the Izala movement pushing for greater adherence to Islamic law,¹⁶ within these walls women wore skimpy tank-tops and thin, hastily tucked wraps. Their heads were bare. Their knees peeked through their skirts as they painted their feet with henna swirls. As time passed, my hair tumbled from my loose head scarf. Women pulled on the collar of my shirt to compare our undergarments. My notions of “appropriate dress” morphed, and as my comfort level with the women grew, my sleeves shortened.

I forgot how conservative their world outside of the intimacy of our shared space continued to be. In a Christian hospital, surrounded by women, the strict religious practice of Maradi seemed immaterial. But of course it was not. Frequently I would run into a group of women with whom I had become close, near the improvised market along the road. If they had not grabbed me, I would not have recognized them. No part of their skin would be visible. They would be covered from head to toe in synthetic black fabric. Long *hijabai*, tailored veils that covered their heads, permitted a kind of mobile seclusion, allowing them to move freely in public space. Dark socks were worn with their flip-flops, black gloves were donned despite the heat, and *niqabi*—layered face veils—were tied around their foreheads, some allowing for eyes to peek through, others meeting onlookers with a solid black panel (figure 3). While I was at first disoriented by the public/private divide, the women at Danja expertly navigated the expectations of piety.



FIGURE 3. Woman in Danja dressed for the market

But it was not without conflict that pious Muslim women came to seek care at a Christian hospital. In Maradi and surrounding villages, rumors circulated of proselytization at Danja (these rumors were not entirely unfounded, as I show in chapter 7). Although Danja arguably offered women the best opportunity for care

in the country (Heller 2017), many women's families discouraged them from seeking care there, preferring that they remain in the state system. The state fistula centers around the country were overburdened and understaffed, while the only thing lacking at Danja was patients.

Without the benefit of ethnographic texture, Danja appears to be the best choice for women seeking treatment, but context matters—and women and their families regularly chose against the center. Just as the experience of fistula in Niger is highly dependent on local context and cultural expectations of marriage, womanhood, and fertility, the experience of treatment-seeking cannot be disentangled from the highly charged and profoundly localized social, religious, and political environments within which fistula care exists. From a distance, the forces—political, economic, socioreligious, and highly personal—that shape realities are blurred. Local conflicts, constraints, and controls are rendered invisible, replaced by generalities—assumptions of a pan-African (or even pan-Global South) experience of fistula.

The Women

Compared with many West African countries, Niger is relatively ethnically homogenous, composed of only eight main ethnic groups. According to the 2010 Nigérien government census, the largest ethnic group in Niger is the Hausa, constituting more than half (56 percent) of Niger's population, followed by the Zarma and its closely associated ethnic group, the Songhai (21 percent of the population). The Hausa are one of the largest ethnic groups in sub-Saharan Africa, with over 40 million people, most of whom live in Niger and Nigeria. The Zarma-Songhai, a highly socially stratified society historically reliant on slavery, are a relatively small ethnic group, concentrated in southwest Niger. Both the Hausa and Zarma are sedentary farmers, living primarily in the arable southern tier of Niger (although the Zarma live predominantly in the west while the Hausa regions are in the central and east of Niger). Hausa and Zarma-Songhai societies are Islamic (predominantly of the Maliki-Sunni school), patrilineal and patrifocal, and widely practice polygyny. Within both Hausa and Zarma-Songhai society, divorce is common and easily attained, but women are expected to quickly remarry.

The remainder of Nigérien people are nomadic, seminomadic, or historically nomadic pastoralists. The seminomadic, Islamic, and traditionally stratified Tuareg live predominantly in the Saharan and Sahelian regions of Niger, Mali, Burkina Faso, Libya, and Algeria and speak a Berber language, Tamasheq. Found primarily in the north of Niger, the Tuareg constitute 9 percent of Niger's population. The Tuareg follow bilateral descent and inheritance patterns and practice oasis gardening, caravan trading, and livestock herding. Tuareg practices have been undergoing significant transformation due to the forces of Islamization and sedentarization, as many Tuareg now live at least part time in villages, resulting in the decline of women's historically high status and relative autonomy (Rasmussen 2004). The Tuareg are underrepresented in government, are often resented

by sedentary ethnic groups like the Hausa and Zarma-Songhai, and are thus politically marginalized. These tensions have led to repeated Tuareg rebellions in attempts to form an independent Tuareg nation-state.

Fulani, also known as Peul, Fula, and Fulbe, are a broad ethnic category of nomadic and seminomadic pastoralists and agro-pastoralists who live predominantly in the semiarid Sahel across West Africa and speak Fulfulde. Dispersed throughout Niger, Fulani comprise 9 percent of the population. Fulani are patrilineal, patrilocal, and moderately polygynous. Much of Fulani identity, tradition, and economic stability revolves around cattle. However, decreases in livestock holdings and increased household economic demands have pushed many Fulani pastoralists to agro-pastoralism, diversifying their livelihoods to reduce risk and increase resilience to environmental and social conditions (Ducrottoy et al. 2017). As with most mobile pastoralists, Fulani still tend to live in geographically marginal, particularly disadvantaged areas.

The remaining ethnic groups of Niger are the Kanuri (found in the far east of the country), who constitute 5 percent of the population, and the Toubou, Gurma, Diffa Arabs and smaller minority groups, who together make up the remainder of Niger's population.

Of the hundred women included in this research, 41 were Hausa, 31 were Zarma or Songhai, 14 were Tuareg, 8 were Fulani, 5 were Kanuri, and 1 was Mossinke from Mali. Although the women's ethnic identities were not considered in developing the research sample, the 100 women are ethnically representative of the population. Hausa women were slightly underrepresented and Zarma women slightly overrepresented in the sample, likely because three of the four fistula centers were located in the capital of Niamey, which is Zarma territory. Although women come to the capital from all over the country to seek care, Hausa women in the east and central regions of the country often first seek treatment in regional hospitals or in Nigeria or Chad. The ethnic composition of the women interviewed at the fistula center outside of Maradi was far less ethnically diverse; 23 of 25 women (92 percent) identified as Hausa.¹⁷

Niger—like so many sub-Saharan African states—is defined by *brassage*, a cultural and ethnic blending or hybridity. Although for ease of quantification I categorize women by their self-identified primary ethnicity (typically that of their father), such labels distort Niger's historical and ethnocultural realities (Alidou 2005). Not only are families often ethnically mixed (ethnically complex family formations are particularly common in the context of polygyny), but in a more abstract sense, ethnic groups are not discrete: they have blended with neighboring groups for centuries. As Ousseina Alidou (2005) has explained, “pure” ethnic groups are a relatively new construct in Niger, reflecting Western conceptions of fixed African identities and emerging from colonial and postcolonial opportunistic politics of division. Nigériens often embody ethnic composites, with synchronous multiethnic and multilingual identities. Many women I came to know were raised bilingual or trilingual, practiced customs with roots in

multiple ethnic traditions, and came from mixed families in historically mixed regions.

In their educational attainment, the women I came to know were a lot like rural Nigérien women generally. According to the Demographic and Health Surveys (INS and ICF International 2013), 80 percent of women in Niger (and 88 percent of rural women) have no public or Western-style education and less than one percent (0.1 percent of rural women) have any education above secondary school. No woman in my sample attended more than eight years of schooling and 89 percent had no primary education at all (although most had some Qur'anic instruction). Even among women who had attended public school and were taught in French, the national language of instruction, none were literate in the language, nor could any woman comfortably navigate more than basic French greetings.

However, women who do not attend French-speaking government schools are not necessarily poorly educated. In 2001, there were more than 51,000 Qur'anic schools in Niger, educating 560,000 students, 35 percent of whom were simultaneously attending Western-style schooling (Alidou 2005). Qur'anic schooling begins when children are around four or five years old, and pupils are taught the basics of reading and writing in Arabic, proper pronunciation of suras (verses of the Qur'an), and the five pillars of Islam. Qur'anic schooling culminates in the memorization (and recitation) of the Qur'an. Secondary Islamic education in Niger takes place in the *madarasa* (*makarantar ilimi*), is taught in Arabic, and involves in-depth study of the Qur'an, Islamic law, classical Arabic, the *hadith* (the sayings of the Prophet Muhammed), and *sunnah* (the tradition of Muhammed). Although the women at centers could not read or speak French, many could recognize and replicate Arabic letters, others could read select Arabic prayers, and nearly all learned from and taught one another what they knew in an effort to become better Muslims.

As is the case with much of the western Sudanic belt (a region which covers much of Niger, Mali, Senegal, and Burkina Faso), approximately 95 to 98 percent of the population of Niger is Muslim (INS and ICF International 2013; Meyer et al. 2007). Around 95 percent of Nigérien Muslims are Sunni, the majority linked to Sufi brotherhoods; the remaining 5 percent are Shi'a. All 100 women I interviewed, all their family members, and all but three of the experts identified as Muslim.

Yet, these 100 women were markedly diverse. They were young and old, with an average (estimated) age of 31 years old, ranging from 15 to 70. They had developed fistula at a variety of points in their reproductive lifespans, from their first to their twelfth pregnancies, ranging from the ages of 13 to 54 (with an estimated average age of 23 years old). They also had a vast range of experience. For some, fistula was an acute condition developed late in life. For others it was a chronic, and lifelong injury. The average amount of time a woman had lived with fistula before I spoke with her was nearly seven years, but the length of time she had lived with

the condition ranged between one month and 50 years. (See the appendix for demographic data.)

Studying Incontinence

Worldwide, around thirty percent of women are affected by female urinary incontinence, a phenomenon that is largely caused by aging, menopause, and childbirth; the incidence increases for women who have had more pregnancies (Al-Badr 2012; Avery and Stocks 2016; Diokno et al. 2004; Li, Low, and Lee 2007).¹⁸ With the highest total fertility rate in the world, Nigérien women are thus quite familiar with some uncontrollable leaking. However, because women cannot see the interior of their bodies, they do not always understand that an abnormal anatomical connection is causing their incontinence.

The Hausa term for fistula, *ciwon yoyo fitsare*, or “the sickness of leaking urine,” highlights effect rather than cause. Locally, researching fistula is not a study of an anomalous condition but of incontinence out of place, a study of degree—a common female malady that has become unmanageable, irregular, “too much.” Women may arrive at fistula centers leaking, with stories of mistreatment, concealment, or social isolation, only to be diagnosed not with fistula but an infection. Although in this book I approach women’s experiences through the frame of fistula—a condition unseen, accessible only through the diagnosis of specialists—the women themselves do not. “Fistula” is a Western, biomedical frame of cause superimposed on women’s experience of effect. It will become clear that this frame does not fit perfectly.

As a doctoral student from the United States with little personal religion and living alone, on the face of it I had seemingly little common ground with the deeply pious, communalist, pronatalist women who populated fistula centers across Niger. Yet, I came to appreciate what connected us, what set us apart from other Nigérien women. Because being under 150-centimeters tall increases a woman’s risk of obstructed labor (and thus her risk of obstetric fistula), fistula centers often house smaller-than-average women. At 4 feet 11 inches (<150 centimeters) and nearly 30 years old with no children; my size, presumed infertility, and apparent lack of familial connection made me seem slightly less alien, slightly more relatable in clinics full of unrepresentatively short, largely childless, often socially isolated women. In time, I forged deep relationships of care and reciprocity with many women at the centers. They came to rely on me for information about their bodies, etiologies of their conditions, hospital timelines, and clinical prognoses. In turn, I relied on them for everything: data, friendship, and essential knowledge on how to be in their world. We bonded over our loneliness, our fears for the health of those we loved for whom we could do nothing, and the disempowering distance. We bonded over music videos played on old Nokia phones, snacks, and monotony. Building rapport across cultural, economic, linguistic, and health divides took time, openness, and humor.

On very hot days, when the prospect of conducting another interview felt particularly onerous, languid afternoons often degenerated into play—or rather, something approximating play but probably closer to a theater of the absurd. When I am in the United States, surrounded by people who understand my cultural references, who value a dash of irony, and who can appreciate the art of self-deprecation, I do all right for myself—I can get by at a cocktail party. But in Niger, lacking the necessary linguistic and cultural sophistication, my sense of humor morphed into that of the stereotypical uncle: trite, somewhat awkward, and often unseemly.

As my relationships with women at centers grew closer, they came to expect and participate in my often intentionally odd and sometimes unintentionally inappropriate behaviors. I began dancing without rhythm. In turn, women would dress me up in their clothing and have me perform “Nigérien” tasks like walking around the yard with stuff balanced precariously on my head. I would tickle adult women. They would pose elaborate photoshoots. I would ask them about orgasms and pornography and draw diagrams of vaginas in the dirt, indelicately explaining the mechanics of use for the tampons they would find in my bag. They would guess my age (usually in the ballpark of pubescent years) and call me *tsofuwa*, or old woman, when they found out that I was 30 (and childless). I have a man’s name (Ali) and sometimes wore pants, so they would tease me, asking about my wife and calling me by male pronouns. I admit, I was mostly a bizarre oddity. Still, it seemed to work for me, particularly in fistula centers where women’s days were typically filled with little but the existential weight of waiting. Play filled our afternoons, deepened our laugh lines, and provided relief from interviews in which women revisited their trauma, exploitation, and loss.

Like many anthropologists, I spent my months in the field navigating the flaws and challenges of the anthropological endeavor—attempting to balance objectivity and self-reflexivity within the ever-shifting political realities of field sites and global currents of power. Anthropology is defined by fieldwork. Our intimate knowledge of a place and its people, and the method by which we choose to engage with our site—ethnography—can, ideally, circumvent the systems that control the flow of information. Ethnography allows our subjects to speak in their own voices. As anthropologists, our job is to amplify those voices, in all their complexity and moral ambiguity.

I take seriously the feminist concern with empathy—an exploration of ethical intersubjective practices and modes of knowing. Yet empathy, as Clare Hemmings writes, “does little to challenge the temporal grammar of the Western feminist subject” (2011, 203). As close as we became, I tried to never forget how different our realities were. Women’s pain, uncertainty, and structural constraints were inescapable and life-defining. As I diligently recorded their suffering, translating their trauma into publications that would advance my career, I was painfully aware that their loss was my gain. Conflicted, I hoped that this process and the words

that I eventually wrote would transcend the theoretical, affecting Nigérien women directly by altering perceptions and shifting interventions. I strove to practice what Nancy Scheper-Hughes calls “good enough” ethnography: within the limits imposed both by outside forces and by my internal struggles to reconcile the cultural self I brought with me to the field, I carefully and compassionately listened, observed, and recorded (1992, 28). What follows are the words of the women, their families, and practitioners in Niger as I heard them.

ORGANIZATION OF THE BOOK

In this book, I examine how a group of Nigérien women navigate physical constraints and reproductive expectations within a postcolonial, neoliberal humanitarian marketplace. I complicate concepts of stigma often tied to fistula and examine how the condition fits into local notions of the body and local structures of support in times of illness. I examine what it means for these women, and their husbands, families, kin, and communities, to seek treatment. I tease out notions of surgical success and examine the clinical encounter between these vulnerable populations and the biomedical establishment in the market-oriented, philanthropic-capitalistic, neoliberal terrain to which health care in the Global South has been relegated.¹⁹ Finally, I explore the harmful, though unintended, consequences of humanitarian representation and intervention, which permeate the ways in which fistula prevention, treatment, and postsurgical reintegration efforts are conceptualized and implemented.

I have organized this book around three main themes: the lived experience of incontinence; clinical encounters; and humanitarian and media representation. As much as this work is about global forces and international exchanges, at its core *Fistula Politics* is an exploration of the intimate—sexuality, love, care, kinship, identity, and emotion. In part I, “Living Incontinence,” I use rich, in-depth, and extended ethnographic research to expose and explore the complexities of fistula’s lived experience. I examine how women and their husbands, kin, and communities conceptualize, talk about, and treat fistula bodies. I look specifically at the ways in which the “sickness of urine” fits into local notions of the body and local structures of caretaking and support in times of illness. I draw from and build upon previous work on incontinence, chronic illness, postsurgical subjectivities, and rehabilitation by Lenore Manderson (2011) and Lenore Manderson and Carolyn Smith-Morris (2010). I explore the links between intimate others, corporeality, identity, and shame among women who have undergone reparative surgeries, and examine their resultant altered self-conceptions. I critically engage with local understandings of aberrant bodies and genitals, shame, and pain. I examine what it means to be a woman who must negotiate reproductive constraints within pronatalist terrains with a body that is perceived as damaged or disabled.

In chapter 2, “Fistula Stigma,” I illustrate the ways that fistula-related social stigma affect women internally and externally, altering their perceptions of self and their relationships with their spouses and co-wives, families, and communities. I unravel popular understandings of stigma and offer new ways to think about the concept. I argue that whether a woman is stigmatized by fistula, and in what circumstances, almost entirely depends on her preexisting social relationships. I demonstrate that, while fistula results in experiences of shame and embarrassment for the majority of women, very few women perceived or experienced mistreatment or social distancing. This contradicts the previous narratives of fistula. I find that the few who experienced social rejection were already socially vulnerable before their fistulas began—they were exceptionally poor, in unstable marriages, or, most importantly, living without the protection of their mothers.

In chapter 3, “Liminal Wives,” I explore the diverse, dynamic, fluid, and complex ways in which fistula and treatment-seeking affect women’s marital lives. Because of the complicated dynamics of polygyny in Niger, fistula offers a unique lens through which the impacts of chronic illness on family life can be explored. Co-wives, who compete for often scarce resources for themselves and their children, can both undermine and prove essential to the ability of wives with fistula to maintain healthy marital relationships.

In part II of the book, “Clinical Encounters,” I use a political economy approach to focus on the clinical encounter between the disempowered woman and the biomedical establishment. I explore the interplay between gender, circumscribed agency, poverty, structural violence, and the biomedical apparatus in sub-Saharan Africa.

In chapter 4, “The ‘Worst Place to be a Mother,’” I examine women’s engagement with health services during labor, demonstrating how organizational failure, pride, corruption, and regional poverty result in delays, deaths, and disability. I offer a counternarrative to the dominant explanatory structures of public health, which too often place the blame for poor maternal health outcomes on the women themselves, their families, and the “traditional” cultures to which they are thought to belong.

In chapter 5, “The Indeterminable Wait,” I look critically at how women engage with the health system once they develop birthing injuries. Drawing from previous research on the history of global capitalism, colonial and postcolonial health services, and clinical encounters in African contexts, I explore how the selective invisibility of certain afflictions (particularly chronic conditions) affects women’s pursuit of care. I investigate the ways in which biomedicine, particularly surgery, is positioned as a “magic bullet.” Yet, I argue, it falls short of treatment objectives—failing to heal the majority of women—and the processes of treatment itself results in increased social marginalization and stigma. And while fistulas may signify bodily, social, and emotional rupture for the women who have them, for those who treat them, fistulas represent economic gain. Women seeking surgeries are

continuously exploited by both private and state-affiliated actors, for whom potential fistula funds from development and humanitarian agencies represent their best opportunity to get ahead.

In the third and final part of this book, “The Marketplace of Victimhood,” I examine how humanitarian organizations represent the bodies of women in the Global South. I challenge, deconstruct, and decenter the archetypical fistula narrative that is circulated and reproduced in the global media and through humanitarian agencies’ appeals to donors. This part of the book offers a critique of methodology, of hasty investigation, and of partial representations—of the ready-made template, the mad-libs of fistula, where a name and an adjective are swapped out but the story is essentially the same. And it is a critique of those of us who perpetuate these fictions—of the media, of humanitarian organizations, of scholars, and of readers who uncritically accept these timeworn narratives about Africa and Africans, particularly those about women who are victims of being African.

In chapter 6, “Superlative Sufferers,” I historically situate humanitarianism in Africa, arguing that representations of women with fistula follow a formulaic and long-standing pattern of engagement with women’s bodies in the Global South, and in Africa particularly. This chapter is heavily influenced by a tradition of anthropological critiques of development, humanitarian aid, global health initiatives, and colonial and postcolonial Western engagement with African bodies.²⁰ I critique the ways in which distant, gendered suffering is passively viewed and consumed, and ultimately commodified and medicalized, by the Global North.

In chapter 7, “Costs and Consequences,” I turn to the conceptual and concrete effects of the humanitarian and media narrative around fistula. I examine the rhetorical links that are frequently drawn between the woman with fistula and the iconic leper, essentializing women and perpetuating a global media and donor narrative of stigma. When the fistula centers assume that women with fistula are the “new lepers,” and treat them as such by physically isolating and segregating them, I show how, like the leprosaria before them, centers may unintentionally cause the social stigma, marital rifts, and declining health that these organizations aim to address. The implicit assumptions created by the dominant fistula narrative about women’s quality of life back home has concrete consequences on fistula prevention, treatment, and rehabilitation programming—consequences that are evident in long wait times at centers, a singular focus on surgery rather than improved management of chronic fistula, flawed reintegration programs, an undermining of women’s concealment strategies, and a disregard for women’s confidentiality. I briefly sketch some policy solutions for these problems in chapter 8, the book’s conclusion.

PART 1

LIVING INCONTINENCE



Portrait of a Zarma woman in Niamey, Niger

LARABA'S STORY

Rejection, Resistance, Refusal

Although she rarely left the confines of the fistula center, Laraba spent hours staring at her own reflection in a palm-sized mirror. Carefully tending to her makeup, she drew dark lines around her lips, above her eyebrows, and down the center of her forehead to the tip of her nose, darkening the distinctive facial scars that mark many Kanuri women from southeastern Niger. Not infrequently, Laraba would find me engrossed in conversation with another woman. She would open my bag, take my camera, grab me by the wrist, and pull me to her room, demanding yet another portrait to capture her modernity. The photograph was always the same: Laraba on her prayer mat, with her pink prayer beads and cell phone in hand—perfectly posed modernity.

At 27 years old, Laraba had lived with fistula for over a decade. She was loud and outspoken, and even (some might say) occasionally abrasive; I often found myself wondering how the formative years of Laraba's young adulthood, spent on the grounds of fistula centers across Niger, had shaped her—how they had hardened her. We all learn to adapt.

When I first met Laraba, she was harsh, quick to issue insults and uninterested in being interviewed. But I suppose I grew on her because after several months she pulled me aside and questioned why I had not asked again to interview her. "We are friends, aren't we?" She was reclining on her bed, attached through a catheter to a bag that was slowly filling with her urine. A week before, she had undergone her eighth surgery. On this day, 10 months after she had arrived at this particular fistula center, she was full of hope and wanted to tell me about her life.

At the age of 14, Laraba was married to an older man—the first cousin of her father. She did not know him; she had not even seen him until she was already his wife. "A young girl's opinion isn't asked. Sometimes, like in my case, she won't even know that she's to be married until the marriage has finished and she has moved to her husband's house," she explained.¹ But Laraba—headstrong even

then—did not want to be married and refused to accept her fate. For one year after her marriage, she resisted her husband and would not pass the night at his home, enacting the same ritual of resistance each evening as soon as the sun set. Yet her intransigence was matched by that of her father. Every night, she fled her marital home. Every night, her father dragged her back to her husband. And every night, she sprinted right back to her parents' home as refuge. Furious at her disobedience and humiliated by her impertinence, her father became violent: "He'd hit me until my blood would redden his hand, but still, I wouldn't go back."

Her mother did not agree with her father's brutality, and she had not wanted Laraba to marry the man in the first place, but, as Laraba said, "wives have no power compared to their husbands." Her mother eventually separated from her father over this, returning to her natal village in northern Nigeria. Laraba was left behind, both because she was already married and because in Niger's patrilocal society a woman may divorce her husband but all her weaned children with him must stay behind. Laraba was left without an advocate—no community elders, no one with sway or say to speak on her behalf. It was Laraba, powerless, young, and female, against her father and her husband, both religious scholars and respected men within the community. Without support, her campaign of resistance did not last long.

What finally made Laraba accept her marriage was neither threat nor physical violence, but, according to her, the nefarious forces of the occult. Laraba's father and husband commissioned a potion from a local sorcerer that was poured over her head while she slept. When she awoke, she had a terrible headache that worsened over the following week. The pain was paralyzing; eventually she had no choice but to submit to her husband. Once she did, the throbbing stopped as abruptly as it had begun.

Although her husband was not unkind, life with him was difficult. Laraba hated him and refused to acquiesce to his demands. When he would ask her to do something, she would refuse. When he told her to fetch water or run errands, she would run into the fields and sit there all day, emboldened by her own defiance.

Laraba miscarried both her first and second pregnancies, which worsened tensions at home. She was resolute that she would not spend her third pregnancy in her husband's home. But when Laraba went back to her father's home, he exploded in anger. He was furious that she continued to disobey his wishes, and he refused to let her stay. So Laraba quietly sold what she owned, cobbling together the necessary funds to cross the porous Niger-Nigeria border. She made her way to the villages surrounding the Nigerian city of Maiduguri in hopes of finding her mother. After a long, arduous, and risky journey, she found her mother's natal village only to learn that her mother had already returned to her father in hopes

of reconciliation. But Laraba's maternal extended kin had opposed Laraba's marriage—they had had their eyes on another young man for her to marry—so they let her stay.

She had been in labor for two days when her aunt noticed that the fetus had changed positions. All the women agreed that this could be dangerous, and eventually they decided to take her to a health clinic. There, Laraba spent three days waiting for care, shuttled between two similarly ill-equipped low-level clinics. On her fifth day of labor, she was no longer conscious. When she awoke, she found herself in a different hospital, lying in a different bed, soaked in a deep puddle of her own urine. She learned that the body of her dead baby had been cut out, and what remained was a hole—a fistula.

Laraba returned to her father's home, but she found life unlivable. She leaked. She had nerve damage sustained from her long labor, and she could not walk as a result. Wet and immobile, she was mistreated. Her father interpreted her fistula as comeuppance for her repeated defiance. Laraba told me how daily life was a struggle: "I cried until I had no more tears left. My father's other wives and their children, they wouldn't eat with me or sit with me. My mother was kind to me, but since she had left my father, even though she came back to him, she had no more power against her co-wives . . . My family didn't care if I was dead or alive, sick or well. They didn't worry about what was happening to me."

Eventually, she made her way to a hospital in Niger's eastern city of Diffa, on the border of Nigeria. After nine months of sleeping on a plastic mat in the hospital courtyard, she was told that they could not operate on her there. She was instead referred to Zinder, a city 500 kilometers to the west. But the doctor at Zinder's maternity hospital would not operate on her fistula until her feet and legs had healed from the nerve damage. Given how difficult her life was at home, Laraba decided to wait at the hospital in Zinder. Without any physical therapy, it took four full years for her legs to regain their function and strength. She was far from her aunt's home in Nigeria, and no one came to visit her during her years in the hospital. In her fifth and sixth year at the center in Zinder, she underwent five operations. None was successful, and with each failed operation her chances for success shrank. "I leaked every day. I leaked all of the time. The operations did nothing," she remembered.

Her father refused to come to see her, and he never sent money. Laraba's husband visited her twice when she was at the center in Diffa, but never again after that. He never sent money either. He married three other women, and the year before I met Laraba he officially divorced her so that he could marry his newest girlfriend and remain within the Islam's limitations of four wives.

The center in Zinder lost its only fistula surgeon, a government employee who had been ordered to move to Niamey, likely due to political rivalries and competition over fistula cases. Eventually, a year later, the center filled a bus with leaking

women and shuttled them 900 kilometers west to Niamey. Laraba remained in Niamey for nearly a year.

At this point in the interview, Laraba became upset and began mindlessly playing with the ringtones on her new cellphone—a gift from one of the many nongovernmental organizations (NGOs) that had passed through over the years. When she looked up, she continued: “We aren’t here because we like it, we are here because we don’t have a choice. Who would bring me back home? With what money? If it wasn’t paid for me to come here to Niamey, I would never have come.”

A week after Laraba told me her story, her catheter was removed. One afternoon I found her curled up on her cot. Through her tears, she told me that the operation had not worked. She was still leaking.

Soon after, Laraba left the center to stay with a distantly related family member in a neighboring town, just outside of the capital. A few months later, I was surprised to see her at an international fistula conference held in Niamey. To open the conference, local representatives had brought along two women to give personal testimonies. Laraba stood in front of the large crowd, looking particularly cosmopolitan in her heavy makeup and shiny pink *hijabi* that shimmered in the light. Through a translator, she told the crowd that because of fistula, her life had been filled with sorrow and problems, but thanks to the doctors and donors she was now dry, and she would have another chance at life. The United Nations Population Fund (UNFPA) reported on Laraba’s testimony in the article “Taking Stock: Ten Years Fighting Fistula in Niger”:

“I wish to launch an appeal to our parents to stop marrying their girls so young.² For me, under the age of 18, a girl should not be married,” said [Laraba Oussman], fistula survivor, 26, after telling her story at the opening of the workshop. She was married at the age of 14. Her fistula, developed during her first childbirth, was repaired only after eight surgeries. “I will now return home and continue testifying. Some women hide. They don’t know what they have and that they can be treated,” concluded Ms. [Oussman]. (Campaign to End Fistula 2013)

At the break, I found Laraba reapplying her makeup in the bathroom. “You’re dry!” I exclaimed as I swung my arms around her, ecstatic about the news. Gazing down, she muttered, “No. I am still wet, but no one wants to hear that story.”

I never understood why Laraba told a room full of fistula experts from across the globe that she was dry. Perhaps she had crafted and deployed her testimony for her own purposes.³ Perhaps clinic staff had asked her to tell the room that she was dry. I often stumble across Laraba’s face on the websites of various NGOs, or in photographs in international news articles on fistula in Niger. Having spent

approximately nine out of the last 10 years in various fistula centers, Laraba had become somewhat of a professional patient. After so many years, she knew how to work within the fistula system.

When I left Niger, Laraba was still waiting at the Niamey center for her ninth surgery. Her family had told her to stay there until she was healed. "Maybe that's forever," she said with a shrug. Forever did not seem far off. Years later, when I last saw Laraba, she had not left the center. By then, she was waiting for her seventeenth surgery.