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Interrogating the Superlative Sufferer: Experiencing Obstetric Fistula and Treatment Seeking in Niger

Alison Heller

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Interrogating the Superlative Sufferer:
Experiencing Obstetric Fistula and Treatment Seeking in Niger

by

Alison Whitney Heller

A dissertation presented to the
Graduate School of Arts & Sciences
of Washington University in
partial fulfillment of the
requirements for the degree
of Doctor of Philosophy

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List of Abbreviations

CNRFO—Centre National de Reference des Fistules Obstétricales (the National Reference Center for Obstetric Fistula)

CSL-Danja—Centre de Santé Léprologie de Danja

DFC—Danja Fistula Center

FGM—Female genital mutilation

Lamordé—the National Hospital of Lamordé

NGO—nongovernmental organization

RVF—Recto-vaginal fistula

SIM-Niger —Serving in Mission Niger

UNFPA—United Nations Population Fund

VVF—Vesico-vaginal fistula

WFF—Worldwide Fistula Fund

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This research revealed the singular importance of mothers. While so many other relationships proved unreliable in the face of illness, time and again, the data exposed the ways in which the relationship between a mother and daughter was steadfast and unwavering. Mothers stood firmly by daughters' sides when others did not. Through years of illness and treatment seeking, women who were lucky enough to have their mothers were protected against the worst mistreatment—advocated for and rarely alone.

My own mother was always my strongest supporter. But the unremitting love that she poured upon me was taken away too soon. And although her desire to see me don a cap and gown fueled her through too many (and yet, not enough) months of painful treatments, she could not live to see me finish.

This is for her.

Abstract of the Dissertation

Interrogating the Superlative Sufferer:

Experiencing Obstetric Fistula and Treatment Seeking in Niger

by

Alison W. Heller

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Professor Shanti Parikh, Chair

Niger is considered the poorest country in the world and has the world's highest total fertility rate. This confluence of extreme poverty and pronatalism (in principle and in practice) situates Niger as a prime site for exploring maternal morbidities, particularly experiences of obstetric fistula, a birthing injury caused by prolonged obstructed labor that results in chronic incontinence of urine and/or feces. This fieldwork was carried out over the course of one year (in addition to two summers) at four fistula centers with one hundred women with fistula as well as thirty-eight family members, husbands, and fistula professionals. In this dissertation I complicate concepts of stigma often tied to the condition, tease out notions of surgical success, explore unintended consequences of humanitarian intervention, and examine how fistula fits into local notions of the body and local structures of caretaking and support in times of illness. This research focuses on how women with fistula experience their condition and treatment seeking and how both their experiences with fistula and their quest for normalcy reconfigure their social and marital lives and their identities of self.

This dissertation has two overall aims. Part I of this dissertation is a critique of representations of obstetric fistula as circulated by the popular media, donor agencies, and in certain circumstances, even some scholarly literature. I argue that the tendency of the donor and media fistula narrative to portray a monolithic “superlative sufferer” both masks the complexity of lived experience and furthers the semiotics of African cultural pathology. I present surgical success findings from my own sample, reconciling my data with the fistula narrative’s expected surgical outcomes. I demonstrate that the international humanitarian marketplace shapes how data are produced and deployed, whereby surgical success rates are translated from clinicians and researchers for public consumption. I explore how the fistula narrative is maintained despite contradicting evidence, looking at the process through which success outcomes are manipulated. Finally, I reveal some of the conceptual and concrete consequences of the Global North’s tendency to consume, medicalize, and commodify distant suffering, both in how we think about Africa and intervention and in how we intervene into fistula and maternal health.

The second aim of this dissertation is to expose and explore the complexities of the lived experience of fistula and to forward an alternate narrative that emerges from rich, in-depth, and extended ethnographic research. Part II and III of this dissertation examine the diverse and nuanced experiences of living with fistula and the ways in which the “sickness of urine” (as it is known locally) permeates a woman’s everyday life, often even after she is “cured.” Specifically, Part II of the dissertation explores marriage, normative sexuality, fertility (and infertility) and childbearing in relationship to fistula. Regarding marriage, I argue that fistula must be understood within a context of constrained, highly structured marriage where opportunities for relationship futures are narrowly defined, and how well a marriage can absorb the shock of illness and injury is depends on variables such as family support, number and rank of co-wives,

length of absence for treatment seeking, and a woman's initial desire to have married. I found that women's marriages were affected in unexpected ways by the onset of their fistulas, sometimes causing rupture, sometimes solidifying marriage bonds and buttressing systems of support between a woman and her husband and co-wife, and other times allowing a woman to exit an unwanted marriage gracefully.

Regarding sexuality, fertility, and labor, I explore how fistula fits into local understandings of aberrant genitals, "broken vaginas," and what it means to be a woman. I specifically discuss a local illness called *'dan guriya*—an umbrella concept covering both abnormal genitals and abnormal sexual behaviors and desires, all of which are treated by a local surgeon through an intervention that frequently causes fistula. Additionally, through the idealized silent, solitary, and stoic homebirth, Nigerien women demonstrate courage and patience through their mastery of pain, gaining social value, internal pride, and embodying womanhood. However, for women with fistula, an idealized birth was not possible. Many women with fistula were expected to brave the extreme physical pain of obstetric catastrophe, only to endure the ensuing social and emotional pain of childlessness and social invisibility and devaluation. Contrary to popular assumptions, I argue that women with fistula did access biomedical care; yet, the quality of care was exceptionally poor as women frequently experienced broken referral chains, the refusal of care, poor-quality care, and inappropriate interventions.

Part III of the dissertation deconstructs notions of fistula-related stigma and reconfigures it as a multi-dimensional concept. I explore how, why, and when fistula-stigma is produced and reproduced, and how local constructions of fistula-stigma serve the interests of various stakeholders and depend on structures of exclusion and inequality. I argue that when and if fistula-stigma is applied depends on a woman's pre-existing social relationships. I found that

experiences of fistula-stigma are highly variable, predominantly internal (rather than external), and largely dependent on broader social and moral contexts that allow for (or prevent) the production of fistula-stigma. The vast majority of women experienced very little external stigma (largely defined by mistreatment or avoidance behaviors) but high levels of internal stigma (shame and feelings of ruined identity and valuelessness), underscoring the personal, emotional, and psychological burden of the condition. I argue that the women who do experience high levels of perceived external stigma are significantly more likely to be living without the protection of a mother. I found that fistula also exacerbates other pre-existing social vulnerabilities, leaving women in unstable marriages, exceptionally poor women, and women who are otherwise unprotected and socially marginalized susceptible to external fistula-stigma, which women embedded in stable social networks were otherwise able to avoid. Additionally, I found that possibilities for postoperative destigmatization depend on women's pre-existing social contexts and local power disparities, resulting in thorough and unproblematic destigmatization for some women and unmitigated fistula-stigma for others—often regardless of surgical outcome.

Chapter 1

Introduction

Fati, a forty-two-year-old Tuareg woman originally from Mali who I came to know at a fistula center in Niger’s capital city of Niamey, developed an obstetric fistula twenty-six years before I met her, following complications during her first childbirth. Although Fati’s fistula had been healed seven years prior, the deep scars left by her fistula continued to mark her everyday experiences.¹

Fati was married to a man she did not know at the age of fifteen. Shortly after her marriage she became pregnant, and when her contractions began, she refused to acquiesce to the supplications of her family to deliver in the neighboring village’s health center, the reputation of which was tarnished due to a string of recent maternal mortalities. Fati, who twenty years later remained just as stubborn, shook her head as she remembered how her resistance remained unwavering, even as her labor failed to progress for two days, then four, and finally seven full days. Even as the days marched on, she reasoned that her chances of survival were better if she stayed home. When Fati finally delivered a stillborn boy, her body had sustained serious internal injuries, leading to the development of an obstetric fistula—an abnormal connection between her vagina and her bladder. Five days after Fati deliver her stillborn son, her injuries led to an unremitting stream of urine that began to flow from her vagina.

As is the experience of many women who develop this birthing injury, neither Fati nor her family had ever heard of such a condition, but for the next nineteen years, much of Fati’s life was dedicated to managing her incontinence and looking for treatment. Fati’s quest for

¹ In this dissertation I will use the term “fistula” as shorthand to denote “obstetric fistula” although technically “fistula” denotes any abnormal pathway in the body.

corporeal (and often social) normalcy spanned five pregnancies, four husbands, three countries, three decades, two living and two stillborn children, one failed surgery, and—finally—one success. But, as I will demonstrate in this dissertation, most women’s pursuit of normalcy does not end at continence.

Fati’s story is one of economic deprivation, only exacerbated by the most recent political turmoil in northern Mali, wherein the rise to power of al-Qaeda of the Islamic Maghreb worsened her ill health and pushed her across the border into Niger. Indeed, Fati’s experiences with her fistula were shaped by her conditions of poverty and the structural violence that surrounded her, where fistula was both caused by and resulted in poverty. Yet, her story is also one of unlikely empowerment and resilience within a context of extreme constraints. Fati’s story spans decades, borders, and marriages. The causal connections are complicated. And contrary to many media and humanitarian portrayals of women suffering from obstetric fistula in sub-Saharan Africa, Fati is anything but passive. Throughout this dissertation, Fati’s words, and the words of ninety-nine other women like Fati, will bring to life how a condition like fistula is experienced, treated, hidden, and integrated into everyday life by a diverse group of women in Niger.

Fati’s story is in contrast to the story of a woman named Hadiza, a story in which causal connections are direct and ethical culpability is easily assigned. Hadiza’s narrative is a familiar one, told and retold in various incarnations about the passive victims of obstetric fistula that dominate the coverage of the birthing injury in the popular media and humanitarian organizations’ portrayals. In “Where Young Women Find Healing and Hope” (2013), *New York Times* Op-Ed columnist Nicholas Kristof presents the story of Niger’s Danja Fistula Center and one of its patients. Selecting women whose stories (or pieces of their story) fit into a

conventional fistula narrative, Kristof highlights the struggles of Hadiza, a particularly young and beautiful patient, whose smiling face shines from the accompanying photograph. Meditating on the hardships endured by Hadiza and women like her, Kristof laments, “there is nothing more wrenching than to see a teenage girl shamed by a 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.

Some were married off at 12 or 13 years old and became pregnant before their malnourished bodies were ready. All suffered a devastating childbirth injury called an obstetric fistula that has left them incontinent, leaking urine and sometimes feces through their vaginas. Most have been sent away by their husbands, and many have endured years of mockery and ostracism as well as painful sores on their legs from the steady trickle of urine...

The first patient we met is Hadiza Soulaye; with an impish smile, she still seems a child. Hadiza said she never went to school and doesn't know her birth date, but she said that her family married her off at about 11 or 12. She knows that it was before she began to menstruate. She was not consulted but became the second wife of her own uncle.

A year later, she was pregnant. Hadiza had no prenatal care, and a traditional birth attendant couldn't help when she suffered three days of obstructed labor. By the time Hadiza was taken to a hospital for a Caesarean delivery, the baby was dead and she had suffered internal injuries including a hole, or fistula, between her bladder and vagina...

Hadiza 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. Worldwide, there are some two million fistula sufferers, sitting in their homes feeling ashamed, lonely and hopeless.

A few months ago, Hadiza heard about the Danja Fistula Center and showed up to see if someone could help. Dr. Steve Arrowsmith, a urologist from Michigan who helped plan this center and has repaired more fistulas than any other American, operated on Hadiza and repaired the damage...

Women who have suffered for years find hope here, and they proudly display skills they are learning, such as knitting or sewing, that they can use to earn a living afterward. As they await surgery, their dormitories echo with giggles and girl talk. They are courageous and indomitable, and now full of hope as well. (Kristof 2013)

I met Hadiza in February of 2013 during my year of fieldwork in Niger researching

women with obstetric fistula, six months before Nicholas Kristof's visit to the Danja Fistula

Center. I knew Hadiza. But, this was not how I would have told her story. Yet, Kristof's take is

a common story of fistula forwarded by a global media, born from a global marketplace that

craves worst-case scenarios, lurid tales in which girls are victimized by African men, abused, neglected, and eventually dismissed and discarded. Tales in which brown-skinned girls must be saved. And Westerners—their goodwill, their dollars, and their surgeons—must save them. Tales in which through Western humanitarian efforts and technological solutions, these women are transformed. Kristof’s story is as much about Hadiza as it is about the Western audience who consumes these tales, simultaneously shocked and captivated by narratives of far-away catastrophe, alleged cultural degradation, and the innocent victims left in the shadows of iniquity and inaction.

According to Kristof, Hadiza is young. Still a child even. She was forced to marry her own uncle. When she got fistula, he threw her out of his house. He had no more use for her. She was shunned. She was ostracized. She was insulted. For years, she endured it. She was hopeless. But then she found the fistula hospital. And it was there that she found hope.

And it is not all false. Hadiza was young. And she was beautiful. But the story Hadiza told me about her life was fuller, richer. Over long chats, leisurely meals, and in-depth interviews during my time at the Danja Fistula Center, I heard a multifaceted story about resilience and the negotiation of constraints. Hadiza was married around fourteen to an adopted son of her grandmother. He was young too, and in Niger family marriages are considered the best kind of matches. She was his only wife. And at the beginning of their marriage they were very happy; they loved each other very much. She told me that although she was married early, they waited years before consummating their marriage. And when she eventually got pregnant, they were joyous. But, her labor went badly and she was left with fistula. Her husband did not divorce her, and he certainly did not throw her out—she grew up with her grandmother, in the

same house as her husband. When she married, she changed rooms, but not houses. Her home was his home.

But, in the face of her health problems, his behavior changed and his love faded. He began to ignore her and to neglect her. After a year with fistula, he took another wife, a practice permitted by Islam and common in Niger. So, she packed up her few things and moved across the courtyard, returning to her grandmother's room. Her new co-wife was unkind. Still, she explained, "Besides him and her, everyone loved me as they had before." "But, I feel ashamed of the urine. I am ashamed that I will wet myself, and people will notice, so I mostly stayed home with my grandmother. My friends came to visit me as they had before. They tried to console me. They told me to be patient, that I would be cured."

Although Kristof suggests that Hadiza began her search for treatment only months prior, during our long talks, it became evident that Hadiza's quest for cure began years before. At the time I interviewed her, she had already undergone six failed surgeries. Some fistulas are hard to close. Surgery is not the silver bullet. After six failed surgeries, it is likely that Hadiza will never go home completely dry.² This long, and often unsuccessful, quest for cure is often left out of simplified and formulaic odes to hope that dominate media and donor agencies' coverage of the injury.

1.1 Fistula-Stigma, Flawed Bodies, and its Global Context

This dissertation has two overall aims. First is a critique of representations of obstetric fistula as circulated by the popular media, donor agencies, and in certain circumstances, even

² Although there is no consensus on how to measure surgical success, which is sometimes used to connote fistula closure and other times meant to reflect regained continence, as much as 55% of women whose fistulas are surgically closed will suffer from residual incontinence—or be perpetually "wet" despite the absence of any remaining abnormal physiological connection (Frajzyngier 2011; refer to chapter five for further discussion).

some scholarly literature. This dissertation is an examination of how distant suffering is viewed, consumed, medicalized and commodified by the Global North.³ Thus, while what follows in these chapters are grounded first and foremost in ethnography—in Clifford Geertz’s (1973) notion of “thick description” where subjects speak of their own experience and give it form, nuance, and context—my work is also heavily influenced by a tradition of anthropological critiques of development (Bornstein 2003; Escobar 1995; Ferguson 1990, 2006; Mindry 2001; Mosse 2005), humanitarian aid (Bornstein 2012; Bornstein and Redfield 2011; Fassin 2012; Feldman and Ticktin 2011; James 2010; Redfield 2005, 2013; Ticktin 2011), global health initiatives (Biehl and Petryna 2013; Nguyen 2010), and colonial and postcolonial Western engagement with African bodies (Comaroff 2007; Cooper 2006; Hunt 1999; Kleinman and Kleinman 1996; Vaughan 1991), among other literatures.

What follows in this dissertation is a critique of the way fistula is branded, packaged, and sold to Western audiences through the global media and humanitarian organizations, and eventually resold and propagated by a Western audience. It is a critique of methodology, hasty investigation, and 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 those of us who uncritically accept these narratives about Africa, about African women, and particularly about women who are victims of being African.

³ In this dissertation I use the terms “Global South” and “Global North” (or, “the West”) to refer to countries sometimes called “Third World” and “First World,” “developing” and “developed,” “low-and-lower-middle-income countries,” or less commonly, “minority world” and “majority world” respectively. Admittedly, none of these binaries adequately encompass the vast diversity and heterogeneity of all of the implicated peoples, nations, or regions. Still, the terms are useful indicators of perceived divisions of the world, its inhabitants, and the allocation of its resources.

In the three chapters of Part I, I challenge, deconstruct, and de-center the archetypical fistula narrative that is circulated and reproduced in the global media and through humanitarian agencies' appeals to donors. I argue that the formula it follows must be seen as an imaginary that is emblematic of a long-standing pattern of engagement with women's bodies in the Global South, and Africa particularly, and with their alleged black male abusers. While the fistula industry positions fistula as highly stigmatizing, this presumed monolithic stigma masks the complexity of lived experience (as well as having many other conceptual and concrete costs and consequences).

The second aim of this dissertation, and where this research makes the largest contribution to work being done on obstetric fistula specifically, and chronic illness and treatment seeking in West Africa generally, is to expose and explore the complexities of lived experience of fistula and to forward an alternate narrative of obstetric fistula that emerges from rich, in-depth, and extended ethnographic research. Part II and III of this dissertation explore the diverse and nuanced experiences of living with fistula and the ways in which the "sickness of urine" (as it is known locally) permeates a woman's everyday life, often even after she is "cured."

This research is about how fistula-related social stigma affects women internally and externally, altering their perceptions of self and their relationships with their spouses and co-wives, their families, and their communities. It is about how fistula fits in to local understandings of aberrant bodies and genitals, shame, pain, and what it means to be a woman while negotiating pronatalist terrains and reproductive constraints. This dissertation investigates the concept of "waiting" as it relates to the fistula experience and prolonged periods of treatment seeking whereby individuals move seamlessly in and out of local and biomedical systems of care, strategically deciding when and if to abandon and reinitiate plans to pursue surgical remedy

for chronic incontinence. Nearly all of the following chapters explore the interplay between gender, circumscribed agency, poverty, structural violence, and illness.

Lenore Manderson (2011) argues that anthropologists have contributed little to the literature involving the personal experience of living with a body altered by illness, perhaps due to anthropology's emphasis on "community and context rather than care and the clinical domain" (46-47). In response to this critique, this project deeply examines the lived experience of women whose bodies are perceived as damaged or disabled. I investigate how their altered (and sometimes infertile) bodies affect their romantic, familial, and community relationships. I draw from literatures on flawed bodies (Buckley and Gottlieb 1988; M. Douglas 1966; Jewkes and Wood 1999; Manderson 2010; Shildrick 1997), social stigmas (Ablon 1984, 2002; Castro and Farmer 2005; Goffman 1963; Jenkins and Carpenter-Song 2008; Link and Phelan 2001; Parker and Aggleton 2003; Yang et al. 2007), experiences of chronic illness (Becker 1994; Kleinman 1989; Manderson 2011; Manderson and Smith-Morris 2010), infertility (Aghanwa, Dare, and Ogunniyi 1999; Bharadwaj 2003; Donkor 2007; Hollos et al. 2009; Inhorn 2004; Kielmann 1998; Miall 1985; Whiteford and Gonzalez 1995), and social disruption due to marriage rupture (Cooper 1997; Bove and Vallengia 2009; Goody 1973; Madhavan 2002; Murdock 1967; M. Smith 1954).

Flawed Bodies, Gender, and Pollution: Social theorists have demonstrated the body's importance in understanding social relations of power and the (re)production of social order and disorder, positioning it as a culturally constituted entity through which norms are reified, discourses naturalized, and collective meanings inscribed (Butler 1990; Mauss 1973; Merleau-Ponty 1945, among others). Bodies tend to be separated into immutable dualities: whole and incomplete, abled and disabled, and ultimately, normal and flawed, with the former tethered to

dominance, power, and social distinction (see Bourdieu 1985 on symbolic violence or Foucault 1976 on biopower) and the latter resulting in devalued social existence and stigma (Fraser and Greco 2005). Flawed bodies are often interpreted not as evidence of a physical event, but as the “corporeal symbol of a fundamental failure or decay of character,” lending flawed-body stigma a valence of morality and justification (Manderson 2011). The flawed body is frequently linked to the female body that manifests polluting disruptions of the ideal (as it bleeds, births, lactates, miscarries, and swells) and thus is viewed as undisciplined and out of control, rendering women themselves as morally deficient and existentially disabled.

However, not all female bodies are seen equally, as race, ethnicity, and disability further distance bodies from the male and abled norm. The female African has historically been viewed as the embodiment of dirt and disorder (Comaroff 1993; Vaughan 1991), while the disabled female body, the leaky body, the infertile body, or the fistula body compound this offense: non-male, non-feminine, grotesque, uncontrollable, and polluting. Indeed, the fistula body is marked both by its foreignness and by reproduction gone awry, evidenced by persistent leakages indicating the lack of bodily—and hence social—control.

Social Stigma: Concepts of social stigmas may elucidate why some individuals are valued while others are discounted, considered dangerous or even grotesque. Defined by sociologist Erving Goffman (1963) as a socially undesirable difference, discrediting attribute, behavior, or reputation resulting from a process whereby one’s identity is “spoiled” by the reactions of others, stigma acts as a social regulatory mechanism of abnormality. According to Goffman (1963), stigmatizing marks may be visible or invisible, controllable or uncontrollable, linked to appearance, behavior, or group membership. Stigma can be separated into enacted or external stigma (actual experiences of discrimination) and perceived or internal stigma (shame

and internalization of stereotypes). Stigma can exert its influence over the lives of the stigmatized through social-psychological processes and quotidian acts of exclusion, rejection, devaluation, structural discrimination, and the limitation of opportunities (Goffman 1963; Link and Phelan 2001). Areas of life affected by social stigma are strikingly similar across conditions and cultures, including: marriage, interpersonal relationships, employment, education, mobility, leisure activities and attendance at social or religious functions (van Brakel 2006).

Expanding on Goffman's work, many scholars have theorized stigma in order to understand where it is located, and how it is assigned, reproduced, reinforced, and resisted (Crocker et al. 1998; Jenkins and Carpenter-Song 2008; Jones et al. 1984; Major and O'Brien 2005). However, the concept of social stigma has evolved from Goffman's "spoiled identity" to a more anthropological formulation which problematizes monolithic categories and accommodates complex social contexts, individual agency to resist, and dynamics of power and exclusion (Link and Phelan 2001; Rhine 2009; Schoepf 2001; Shih 2004; Thoits 2011; Yang et al. 2007). Individual-focused theories lead to a conceptualization of stigma as a static attitude rather than a dynamic, and frequently resisted, social process (Parker and Aggleton 2003). However, many scholars assert that stigmatized individuals do defy and transform stigma through various quotidian acts of resistance including avoidance, concealment and attempts to "pass," creation of support structures, and explanatory models which attribute stigma to prejudice or discrimination (Riessman 2000; Whittaker 1992). Situated within the "political economy of social exclusion," or the larger context of power and domination, stigma cannot be reduced to a cognitive process. Rather, it resides in the *social interaction* between an individual with a perceived difference and others who negatively evaluate that difference and have the social power to exert their cognitions, reinforcing mechanisms of exclusion and strengthening

social inequities of class, race, gender, and sexuality (Castro and Farmer 2005; Green et al. 2005; Link and Phelan 2001, Parker and Aggleton 2003).

Stigma and Obstetric Fistula: In contexts where a full transition into adulthood is predicated on reproductive success and a woman's worth is based on her purity, sexual submission, and role as wife and mother, fistula-related stigma may be interpreted as a way of reinforcing gender expectations and controlling women's sexuality (Browner and Sargent 1996; Roush 2009). In pronatalist contexts reproductive failure may lead to the loss of social status, economic instability, individual experiences of "role failure," and ultimately stigmatization, which works to uphold the status quo (Caldwell and Caldwell 1990; Jiggins 1994; Inhorn 2004; Miall 1985; Whiteford & Gonzalez 1995). Yet, not all women with fistula experience fistula-stigma. As is explored in Part III, it takes power to stigmatize (and in turn, lack of power to be stigmatized), and often fistula only exacerbates pre-existing social vulnerabilities.

However, non-profit, public health, and religious organizations (not to mention academic endeavors) may unintentionally reify stigmatized identities in order to *change* the status quo locally and communicate simplified social realities to a removed (Western) audience (Fassin and Rechtman 2009; Feldman and Ticktin 2010; Redfield 2006). Organizations and scholars often present a monolithic imaginary of the woman with fistula. Depicted as a pubescent pariah, victimized by harmful cultural practices, destitute, and uneducated, she performs a "charismatic suffering" (Kleinman et al. 1997; Malkki 1996, 2010; Wark 1995; see for example Little 2010; Naifou et al. 2007). Systemic factors that produce maternal risk such as structural inequalities, poverty, and crippled health care systems are underplayed in order to galvanize western audiences to invest financial resources (Kleinman and Kleinman 1996). However these messages are not consumed only by western audiences; through interventions, advertising, and

outreach efforts, the semiotics of fistula produced by national and international actors are fed back to local communities.

Stigma as a Dynamic Process and Destigmatization: While social stigmas have been extensively theorized, resulting in various conceptual models of stigmatization processes, there is a paucity of theoretical investigations of ways in which stigma may be reduced, modified, or erased (Coulter and Maida 2005; Haightat 2001; Spencer 2006; Trice and Roman 1975; Warren 1980). Destigmatization research is tackled most frequently in the domain of public health or development, endorsing what Gussow and Tracy (1970) refer to as the “destigmatization theory,” the belief that stigma is the result of “myths or misconceptions,” and thus the dissemination of “correct” information will change community attitudes, promote social integration, and ultimately reduce or remove social stigma (Krishnatray and Melkote 1998). This approach has been criticized for overlooking root causes of stigmatization such as social structures, symbolic meanings, and power differentials (Dutta-Bergman 2006; Read et al. 2006; Read and Haslam 2004; Mehta and Farina 1997; Melkote et al. 2008). Some anthropological work suggests that despite treatment, increased knowledge, and social awareness that a condition is treatable, stigma is “tenacious,” “chronic,” “a persistent predicament,” or “sticky, enduring, and difficult to shed” (Warren 1980: 68; Albrecht et al. 1982: 1326; Best 2004: 61; Link and Phelan 2001: 8; Barrett 2005; Pescosolido et al. 2008; Freidson 1970; Scambler 1989).

Recent work on post-surgical bodies also affirms the difficulty for individuals to shed stigmatizing sick roles in the public imagination, often failing to “re-establish normalcy” (Crouch and McKenzie 2000; Manderson 1999: 392; Manderson 2011; Maynard 2006). Some scholars discuss “overcoming stigma,” “stigma reduction,” or “curing stigma” (Hinshaw 2007; Jenkins and Carpenter-Song 2008; Rafferty 2005; Whittaker 1992). Yet, this work focuses

primarily on individual or collective resistance to stigmatized identities, particularly through “passing,” an individual attempt to conceal discrediting signifiers, or treats destigmatization as an implicit result of the erasure of stigmatizing characteristics (see Coulter and Maida 2005; Navon 1996). Other scholars discuss “destigmatization strategies” (Bursell 2012), or ways in which “ordinary members of stigmatized groups” resist ‘spoiled identities,’ exert agency, and “respond to exclusion by challenging stereotypes that feed and justify discriminatory behavior” (Lamont 2009: 151). While it is widely recognized that stigmatizing attitudes are resistant to change, there is evidence that sometimes these attitudes *do* change, and sometimes groups and individuals *are* able to shed stigmatized identities (Spencer 2006). In opposition to previous destigmatization theories, chapter eleven suggests that a woman’s ability to shed fistula-stigma may have little to do with her physical transformation, and more to do with the social network within which she is moored.

1.2 Obstetric Fistula

Obstetric fistula results from prolonged and obstructed labor whereby protracted pressure of the fetal head against the vagina, bladder, and/or rectum damages soft tissue, starving it of blood and eventually producing pressure necrosis. Once the fetus is delivered, the necrotic tissue sloughs off, producing a hole—an abnormal pathway between the vagina and bladder (vesico-vaginal) and/or rectum (recto-vaginal) and thus resulting in persistent incontinence of urine and/or feces through the vagina. If this process is not interrupted by delivery, which usually requires biomedical intervention such as cesarean or forceps delivery, the obstructed labor can last several days and in 95% of the time results in the death of the fetus (Wall 2012; Wall 2006).

Depending on the positioning of the fetal head during the obstructed labor, a vesico-vaginal fistula (often referred to as “VVF”) or a recto-vaginal fistula (referred to as “RVF”), or both may occur. VVF occurs when the tissues between the vagina and the bladder are destroyed during labor, resulting in an abnormal connection between these organs. As a result, with a VVF, urine runs uncontrollably through the vagina. Symptoms depend on the size of the fistula and can range from watery discharge, to urinary stress incontinence (leaking urine at times of increased abdominal pressure such as laughing or coughing), to the unremitting and continuous flow of urine (Rahimi, Capes, Ascher-Walsh 2013).

With an RVF, a hole forms between the tissues of the rectum and the vagina, leading to the uncontrolled passage of feces or gas through the vagina. RVF most commonly results from tissue necrosis following obstructed labor, but an RVF may also be caused by poorly executed episiotomy, performed either by village midwives or poorly trained government midwives or nurses in low-level health centers, whereby in order to enlarge a woman’s vaginal opening her vagina is cut down to her anus.

Within my research sample of one hundred women with fistulas, eighty-five women had vesico-vaginal fistulas, eleven women had vesico-vaginal fistulas *and* recto-vaginal fistulas, while only four women had only recto-vaginal fistulas (see Figure 1.1). Their stories will be presented in this dissertation.

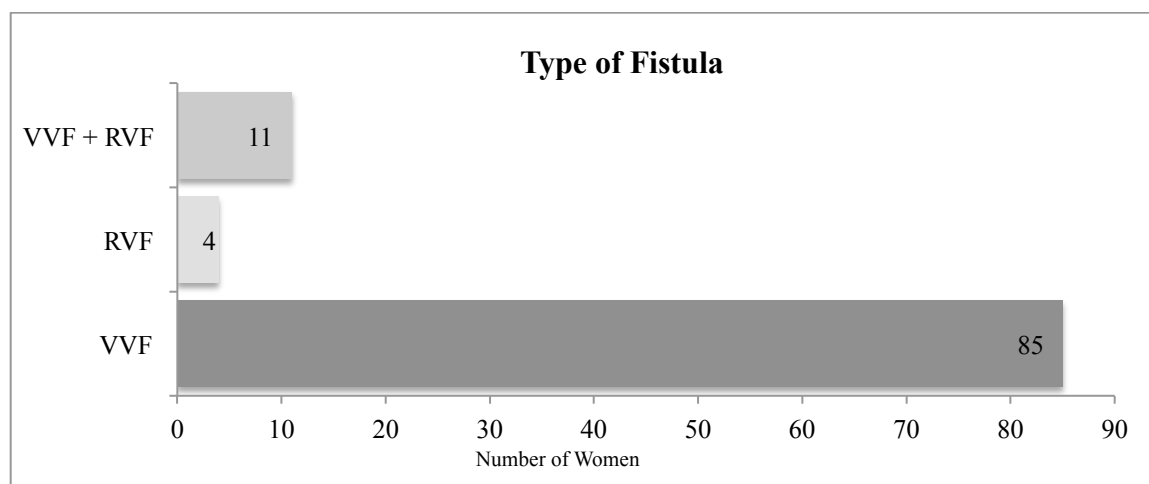


Figure 1.1: Type of fistula among 100 women in research sample wherein 85 women had VVF alone, 11 had VVF, and RVF and 4 had RVF. All data in figures and tables throughout the dissertation are collected by author unless otherwise stated.

It is useful to think of fistula as the result of a “field injury” to a broad area, or part of the “obstructed labor injury complex” as described by Arrowsmith, Hamlin, and Wall (1996) whereby fistulas are often complex and accompanied by multiple birth-related injuries which may include injury categories including: acute obstetric injury, urologic injury, gynecologic injury, gastrointestinal injury, musculoskeletal injury, neurological injury, and dermatological injury (Wall 2012). Specifically, women with fistula commonly suffer from nerve damage, foot drop, stress incontinence, vaginal scarring, secondary infertility, renal failure, tissue loss, urethral loss, cervical destruction, amenorrhea, and/or pelvic inflammatory disease, among other problems.

Although fistula can cause a woman health problems, such as infections, skin conditions, and kidney damage from her attempts to manage the condition through the limitation of fluids, as she heals and regains her strength, a woman can live a long and largely healthy life with this chronic condition. Indeed, the consequences of chronic fistula are often considered predominantly social and can vastly vary. According to Lewis Wall (2012), some of the

“psychosocial” injuries associated with fistula are: social isolation, divorce, worsening poverty, malnutrition, post-traumatic stress disorder, and depression, sometimes leading to suicide.

Although small, fresh fistulas are sometimes closed with catheterization alone, surgical intervention is considered the most promising treatment for obstetric fistula. Under ideal conditions, Wall (2006) reports that first time operations offer women the best chance of success, but, likelihoods of success of repeat repairs decrease precipitously following first operations (see chapter five for a discussion on surgical success).

1.3 Fieldwork in Context



Figure 1.2: Map of Niger and its eight regions, with the Niamey and Danja field sites indicated. Note, three of the field sites were found within Niger’s capital city of Niamey. *Map drawn by author*

Niger is considered both the poorest country in the world and has the world's highest total fertility rate. This confluence of extreme poverty and pronatalism (in principle and in practice) situates Niger as a prime site for exploring experiences of obstetric fistula—a birthing injury often directly attributed to poverty and the resulting lack of access to quality emergency obstetric care.

A large landlocked West African country situated to the east of Mali, to the west of Chad, to the north of Nigeria and Benin, and to the south of Algeria and Libya, Niger is comprised of 1.27 million square kilometers. It is divided into eight administrative regions, which are further divided into sixty-three subdivisions. The population is estimated at 17.1 million, with a low and unevenly distributed population density of 13.5 people per square kilometer.⁴ Niger is growing at one of the fastest rates in the world—3.9% per year because infant and child, as well as maternal, mortality rates have dropped due to intensive national and international attention to maternal and child health interventions. Additionally, fertility rates have actually increased (from 7.0 in 2006 to 7.6 in 2012), health infrastructure has improved, and many migrant workers have recently returned to Niger following political tumult in neighboring countries (particularly in Libya, Mali, and Nigeria) (DHS 2006; DHS 2012; World Bank 2014).

With the highest total fertility rate in the world at 7.6 births per woman (far surpassing the second highest total fertility rate in the world, Uganda at 6.2 births per woman), low rates of access to emergency obstetric care, and last place (187 of 187) on the United Nations Human Development Index, it is unsurprising that Niger has poor maternal mortality and morbidity outcomes (DHS 2012; HDI Niger 2013). The maternal mortality ratio, or the number of maternal deaths per 100,000 live births—often used as a proxy for a country's maternal health

⁴ Only 2.8% of the population living in the arid administrative region of Agadez found in the Sahara, which covers 53% of Niger's surface area.

and the quality of its health care system generally—was estimated by the World Bank in 2013 as 630/100,000 (a marked improvement since 2005 when the MMR was measured at 760, and 850 in 2000) (World Bank 2014).

Although the incidence and prevalence numbers are of quite poor quality, and often the result of opaque methodologies and “guesstimates,” Niger is believed to have one of the highest rates of obstetric fistula occurrences in the world, estimated by Johns Hopkins epidemiologist Saifuddin Ahmed to be between 700 and 800 new cases a year (IRIN 2007a; Ahmed and Genadry 2013).⁵ At the current capacity, Niger’s fistula centers operate on a combined total of 500 to 600 cases a year. Even assuming that 1) there are no more new cases of fistula, and 2) that all of those 500 to 600 operations are successful (both premises are highly unlikely), Ahmed estimates that it will take over 26 years to clear Niger’s backlog of fistula patients (Ahmed and Genadry 2013).

The Nigerien Health System

The Nigerien health system is organized as a pyramidal structure with three levels: the bottom of the pyramid—the local level—including 2,160 community health centers (called *cases de santé*, literally translated, health huts) supervised by community health workers and offering only the most basic services—these health centers are often birthing women’s entrées into the health system and are most effective when used as a point of rapid referral to higher levels of care. However, as will be discussed in chapter nine, these community health centers can actually prove deleterious to women’s health when referral systems move horizontally rather than vertically or are delayed. These health centers are managed by 829 integrated health centers

⁵ Incidence and prevalence rates are notoriously poor and unreliable for obstetric fistula (which will be discussed at greater length in chapter five) but most commonly cited as a prevalence of 2 million women in the Global South with an incidence of 50,000 to 100,000 new cases a year.

(*centres de santé intégrés*), each of which are headed by a nurse. At the next level of care are 33 district hospitals, 26 of which have operation blocks. The intermediate level of care includes eight regional hospitals and two maternity reference centers. The top of Niger's health pyramid consists of three national hospitals and one national maternity hospital, of which one of the field sites—l'Hôpital National de Lamordé—is one (République du Niger 2011).

Paralleling the public health system exists a private system that is composed of missionary medical centers and private for-profit health centers, which have clinics and more specialized care including hospitals and laboratories. The private system is composed of 30 clinics, 43 medical offices, and 4 hospitals, of which a second field site—the Danja Fistula Center—is one (République du Niger 2011). Most private health centers are staffed by physicians who also work in public hospitals, but for a premium price, offer patients their services more quickly during evenings and weekends hours. Due to the long wait times in the over-burdened public system, for those who can afford it, the private system may offer patients the best chances of being seen as non-urgent surgical cases in the public system are often forced to wait untenable stretches of time. Those who are able will often pay double the price (or much more) to be seen quickly.

In four of the eight regions in Niger, there is one doctor for more than 100,000 people, and in all of Niger, there is estimated to be approximately 2 doctors for every 100,000 people (compared to the United States where there are approximately 250 doctors for every 100,000 people, or Cuba where there are 591 doctors for every 100,000 people) (République du Niger 2011). Not only is the medical workforce in Niger profoundly understaffed, despite the vast majority of Niger's population living in rural areas, its medical workforce is highly overrepresented in urban areas and underrepresented in rural areas, with 33% of all medical

workers and 40% of all midwives concentrated in Niamey (République du Niger 2011). Indeed, although 82% of Niger’s population lives in rural areas, only 19% of nurses, 8% of midwives, and 0% of doctors work in rural areas (World Bank 2014; République du Niger 2011).

With high rates of fertility, women in Niger have many occasions to experience obstetric complications, and with a dramatically understaffed and unevenly distributed health care workforce, women have few opportunities to receive high quality health care. As a result, birthing injuries such as obstetric fistula are quite prevalent in Niger, which is consistently ranked in the bottom ten in Save the Children’s “State of the World’s Mothers” report (Save the Children 2012; 2014) and was named in 2012 the “worst place to be a mother” (BBC 2012). Additionally, because the public healthcare system is so overburdened, before movements to create private fistula centers removed fistula treatment from general hospital grounds, women like Fati and Hadiza had very little chance of receiving fistula repair surgeries, as limited resources require triaging decisions that prioritize urgent cases over chronic conditions.

1.4 Introducing the Four Fistula Centers

This fieldwork was carried out over the course of one year (in addition to two summers) at four fistula centers, three of which were located in Niger’s capital of Niamey, and the fourth of which was located in the Eastern region of Maradi. Although all four sites were considered “fistula centers,” they were quite distinct, characterized by a varying spectrum of services and opportunities for women. For example, only one of the four sites offered women regular surgeries.⁶ One of the centers billed itself as a “waiting and reintegration center,” offering women with fistula a place to live, eat, wait, and receive various trainings, but not to receive

⁶ However, none of the sites were able to offer women with complex fistula regularly scheduled interventions (the details of which will be discussed further in chapter five).

medical care. Two centers were connected to a hospital or general medical facility, while two were situated in residential neighborhoods, hidden among houses and huts and far off paved roads. One center was even located within a rented family home, where the master bedroom had been transformed into the office and examination room. Only one center had a fistula surgeon on the premises full-time, while one center had no affiliation with any doctor at all. One center used state-of-the-art equipment and medications, most of which was imported from the West, while another connected women's catheters to the ubiquitous black plastic bags given out at corner stores. Some centers offered women activities and programs; others offered women little more than a shaded place to spend their days, months, or years waiting. Indeed, the quality and content of "care" in fistula centers across Niger varied remarkably.

The Danja Fistula Center: High Quality Care Far From the Capital

The first quarter of my research sample (25 women with fistula) was drawn from the Danja Fistula Center (DFC), a privately run center located 500 miles east of the capital Niamey near the city of Maradi. Maradi, the third largest city in Niger with a population of 175,000, is predominantly ethnically Hausa (with a large ethnic Fulani and Kanuri minority population) and is known as a religiously conservative city and an economic hub within Niger due to its proximity to the Nigerian border. Danja, located fourteen miles south of Maradi, is only seventeen miles from the Nigerian border and forty-two miles from the northern Nigerian metropolis of Katsina.

The Danja Fistula Center (DFC) is run by the secular organization the Worldwide Fistula Fund (WFF), however, it shares a campus (and an administrative partnership) with CSL-Danja (*Centre de Santé Leprologie de Danja*, or, the Danja Leprosy Health Center), a health center and leprosarium run since the 1950s by the evangelical Protestant mission organization SIM-Niger

whose local ministry encourages the physical and spiritual well-being of patients through treatment and religious conversion (see Cooper 2006). SIM-Niger (a local branch of the parent mission group SIM, originally known as Sudan Interior Mission, later Society for International Missions, and finally Serving in Mission)—whose objectives are fundamentally non-secular—and WFF (a secular 501c3 nonprofit)—entered cautiously into a partnership in 2008 to construct a 42-bed secular fistula center on the grounds of CSL-Danja. Despite the dissonant goals, SIM-Niger was pushed towards partnership with WFF due to financial pressures (as the health center was moving towards insolvency largely because fundraising for leprosy had become more difficult as their patient base shrunk due to advances in leprosy treatment; see chapter six) while WFF needed an established presence in Niger, land, and people on the ground who could help navigate the quotidian bureaucracy of building and starting a hospital. Due to the sometimes radically different objectives of the two groups, the tenuous partnership resulted in not infrequent tension, but in spring 2012 the center was opened.⁷

Compared to other health care facilities in Niger (and specifically the three other fistula center sites in this study), the DFC had the most impressive facilities, highest standards of care, and largest focus on holistic treatment. Abutting CSL-Danja and its hospital facilities was the DFC, which was comprised of three separate buildings—the surgical block, the administrative buildings, and the ward. Near the ward was “the village,” or six identical concrete huts where women who were waiting for surgery or women’s accompanying family member could wait, a kitchen (where women in “the village” were served three meals a day), bathroom facilities, a shade structure, and a water pump. Life in “the village” was somewhat removed from life in the

⁷ The Danja Fistula Center was opened under the direction of Dr. L. Lewis Wall (as well as several other key stakeholders), a Washington University Medical School surgeon and anthropologist, an expert on fistula (see Wall 1998, 2002, 2006, 2012, 2014), and a member of this dissertation committee. However, due to security concerns involving activity of Jihadist and Islamist militant groups al-Qaeda of the Islamic Maghreb and Boko Haram, I spent the least amount of time at this site, totaling only 4.5 months including summers.

hospital as women participated in daily programming including literacy courses, courses on health, hygiene, and family planning, and courses covering small business skills and income generating activities. Women spent their days learning how to sew, knit, embroider, or make soap, lotions, and perfumes. They learned how to market these goods once they returned home. Women learned how to budget, save, and make rotating loans within small women's groups within their villages. Additionally, women attended physical therapy courses to learn strengthening exercises for their continence mechanisms and—for women who had sustained nerve damage to their lower limbs—for their feet and legs.

Twice a week the on-staff fistula surgeon, a Cuban-trained surgeon from Burkina Faso, and his nursing staff held clinic, examining all patients in “the village” and ward. Once a week DFC staff performed operations. In contrast to other centers in Niger—even those dedicated to fistula surgery where women wait months for surgeries, DFC offered many women rapid intervention with the aim of respect and dignity. However, because the on-staff surgeon was relatively new to fistula repair, he was limited to operating on the simpler cases of fistula. Although at its conception, DFC was envisioned as becoming a training center for fistula repair in the region, at the time of my research, the on-staff surgeon was relatively new to fistula surgery and lacked the expertise to operate on complicated cases. As a result, many women were forced to wait months for a more experienced fistula surgeon to pass through (the theme of ‘waiting’ will be explored in chapter two).

Lamordé: Housing Women at Niger’s University Hospital

The bulk of my research period was spent in Niamey split between three fistula centers. The first two centers were run by the State: *l’Hôpital National de Lamordé* (the National Hospital of Lamordé; known simply as “Lamordé”) and the *Centre National de Reference des*

Fistules Obstétricales (or the National Reference Center for Obstetric Fistula; called “CNRFO”). These two centers were operated by the Nigerien State as one integrated unit.⁸

Whereas Lamordé offered fistula surgeries, CNRFO was intended to house women before or after their surgeries. Lamordé fistula center was located at Niger’s only university hospital, and thus Lamordé was intended to house women short-term immediately pre- and post-surgically. Lamordé’s accommodations for women with fistula were the least developed of all four centers, consisting of a small semi-private walled-in area, but located in a highly trafficked part of the hospital grounds near the main entrance where the social workers’ offices were located. The women with fistula at Lamordé had one room with eighteen beds with a television in the corner, a small outdoor covered concrete shade structure, outdoor bathroom facilities, and an outdoor yard facing the main access road of the hospital. In theory, CNRFO housed women either before they were scheduled for surgery or during post-operative “reintegration” programming. In practice, this division was not functional as CNRFO was regularly over-capacity and thus women were sent to Lamordé to wait to be scheduled for surgeries for periods of several months. As a result, often the eighteen plastic mattresses in Lamordé were continuously all taken, and all spaces under the semi-private covered concrete structures were claimed by sleeping mats, leaving many women and their family members to sleep in the non-private outdoor yard abutting the paved access road to the hospital. Women frequently complained of vandalism—losing money and cell phones during the night, and were embarrassed by the treatment they experienced by passers-by—hospital patients or their

⁸ Although I originally attempted to draw twenty-five women from each site, these attempts were somewhat in vain as throughout the duration of my research women frequently moved between two or sometimes all three Niamey-based sites. Because CNRFO was the only site offering women surgeries (however infrequently) by the end of my research period, many women ended up at this site, even if at the beginning of my fieldwork (and at the point of our initial connection) they were connected with one of the two other sites.

visitors—who commented on the smell emanating from the women in the yard. Of all of the centers, Lamordé afforded women the least space, privacy, or dignity.

For political reasons unrelated to these observations regarding the quality of care provided at Lamordé, some months into my fieldwork, fistula operations were discontinued at Lamordé, and women were relocated over the Niger River and across town to CNRFO. Except for the occasional overnight visit for a blood test, x-ray, or ultrasound at the hospital, women with fistula were no longer being sent to Lamordé. In May 2013, an operation block that had been constructed years before on the campus of CNRFO (but had never been fully operational) was officially opened. In theory, CNRFO could provide holistic care within the center's walls; women no longer needed to leave.⁹

CNRFO: Niger's Main State-Run Fistula Center

Located in the Sonuci neighborhood of Niamey, along the Tilabéri road, the *Centre National de Référence des Fistules Obstétricales* (CNRFO) received both simple cases and countrywide referrals for complex fistulas from across Niger. With six rooms, thirty-six beds, several administrative offices, outdoor bathroom facilities, two operating rooms, a consultation room, a sewing room, and an outdoor shade structure, the center offered women moderately comfortable long-term housing. Although the administration regularly told donors (as they had initially told me) that women did not stay longer than three months, women regularly lived at the center for several months at a time, and as long as two years (see chapter two) waiting to be scheduled for surgical interventions. Sometimes women punctuated prolonged stays at the center with visits home, returning in hopes of undergoing another surgery. Women with particularly complex cases for whom the center could not offer immediate surgical solutions, or

⁹ This is with a few caveats—CNRFO did not have a blood bank and thus could not offer operations to women who ran a higher risk for heavy bleeding (for the record, neither did Danja).

women whose surgeries repeatedly failed, experienced a pattern not dissimilar to seasonal migration—returning home for holidays or for the rainy season when their labor in the field was needed for their family’s annual agricultural success and then returning to the center in hopes for cure, for economic reasons, or motivated by the social fellowship that the center offered.

Dimol-Niger: A Waiting and Reintegration House in Niamey

The center that housed CNRFO at the time of my research was built and established in 2004 by the nongovernmental organization (NGO) Dimol-Niger (a Fulani word meaning “dignity”). The organization Dimol (whose official name is sometimes listed as Dimol-Niger, *Organisation pour la Promotion et l’Epanouissement de la Femme Nigérienne*—Organization for the Promotion and Thriving of the Nigerien Woman—and sometimes Dimol-Niger, *Santé de la Reproduction Pour une Maternité Sans Risque*—Reproductive Health for Safe Motherhood) was one of the first NGOs in Niger to become involved in fistula prevention, treatment, and reintegration work. Dimol’s president, midwife Salamatou Traoré, raised funds and international awareness about fistula from large multinational organizations. With aid from the American Embassy (and other donors, including the Spanish government and the United Nations Population Fund), Dimol opened the fistula center to house women with fistula in 2004. However, in 2008 the government took back the land the center was on (effectively taking the center) under claims of mismanagement.

Believing that the State’s actions were unjust, and thus that a judicial injunction would return the center to them, Traoré and Dimol staff rented a three-bedroom home across the street from the center, hoping to only temporarily house the women until they could return. In 2015, they were still located in this house.

The house had twenty beds that filled the two bedrooms and the living room, leaving the back bedroom as an office and consultation room for the on-staff midwife. The NGO Dimol billed itself as a “reinsertion” or “reintegration” center, a term used in the fistula world to refer to the process by which a woman with fistula who was once stigmatized due to her condition is healed and returned home with new social (and economic) tools to promote social transformation. However, due to the extremely strained relationship Dimol had with Niamey’s sole purveyor of fistula surgeries—CNRFO (due to the center’s history), the staff at Dimol was not actively involved in securing surgeries for women.¹⁰ If women were not getting repaired, women could not get “reintegrated.” So, in actuality Dimol was more of a fistula waiting house, doing little more than housing, feeding (and some claim exploiting) women with fistula for indefinite periods of time.

Although when I interviewed Dimol staff they made it clear that their job was to offer women support through the surgical process, to provide services post-operatively, and not to secure surgeries for women—a task which was the woman’s alone, all women at Dimol who I interviewed or spoke with informally on the subject claimed to be unaware that the responsibility for locating a surgery was their own. According to women, they were told to wait, and they were told that eventually they would be scheduled for an operation. So women waited, and they waited for years, unaware that Dimol’s administration was not actively looking for surgeries at all.

¹⁰ The only medical solution offered to women with fistula at Dimol was that of catheterization. Upon arrival, Dimol staff placed a foley catheter in most women. Although there is evidence that catheterization for small, fresh fistula may be an effective treatment for closing some fistula, prolonged catheterization may also result in infection and discomfort for women. Many women at Dimol were catheterized for several months at a time.

1.5 Research Methods

This research was conducted over the course of a year, in addition to two summer research trips, in four fistula centers in Niger with one hundred women with fistula from seven ethnic groups. I also included the perspectives of nine family members and five husbands of women with fistula, and twenty-three experts, including practitioners, fistula specialists, individuals working with fistula-related nonprofits, social workers, midwives, and village surgeons (see Table 1.1). These mixed methods aimed to address gaps in existing fistula research—specifically the lack of women’s voices, the absence of women’s experiences on the treatment process itself, a long-term engagement with women, and the integration of both qualitative and quantitative methodologies.

I observed daily life at the centers, conducted focus groups, and in-depth interviewed one hundred women. My research questions focused on how women with fistula experienced their conditions, how their experiences reconfigured their social lives, how fistula affected their identities of self, and how they experienced the process of treatment seeking and its effects on their social lives. Using both quantitative and qualitative instruments, I gathered data on women’s 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 peri- and post-surgical experiences (specifically social, economic, and emotional changes). I was able to examine how fistula closure and restored continence affected women’s lives by also including in my sample twelve women who were previously healed of fistula (rather than attempting to prospectively study the phenomenon).

Because family members of a woman may be more attuned to or willing to report stigma experiences, may have their own motivations that either facilitate or impede processes of destigmatization, their perspectives were essential to this research (Yang et al. 2007). I conducted in-depth interviews with nine family members and five husbands of women with fistula, and conducted two focus groups with mothers, stepmothers, sisters, and aunts who had accompanied their family members to fistula centers (see Table 1.1). I asked family members and husbands about their personal beliefs and attitudes regarding fistula, or the “sickness of urine,” self-reported changes in their own behaviors and the behaviors of others towards the woman with fistula after the development of her fistula and/or her repair surgery (when relevant), understandings of community member’s views on fistula, and how treatment seeking had affected the woman and her social relationships.

Additionally, in order to include the perspectives of actors who comprised a woman’s social space and to better understand the perspectives of various stakeholders in the fistula landscape, I interviewed twenty-three experts. This group included medical and social service practitioners (nurses, doctors, and social service practitioners who worked with women with fistula), religious leaders and village surgeons and midwives, and health and development professionals (individuals with positions of responsibility in secular organizations advocating for fistula prevention, treatment, or reintegration, including with nonprofit organizations). Individuals from these groups were recruited purposively and interviewed regarding both their personal beliefs and their organization’s perspectives regarding fistula in order to shed light on how organizations create discourse and reify categories surrounding fistula.

I was able to conduct eleven post-surgical follow-up interviews with women with fistula or women healed of fistula in their homes. Also, I conducted twelve focus groups with women

with fistula, covering topics such as concealment, management, sexuality, and gender expectations. All of these interviews and focus groups rendered over 350 hours of voice recordings, many of which were transcribed.

In-Depth Interviews	
Women with Fistula	100 <ul style="list-style-type: none"> • 25 from Danja • 21 from Dimol • 52 from Lamordé/ CNRFO • 2 from Maternité Issaka Gazoby
Home interviews with women with fistula	11
Healed/ “Dry” women (formerly with fistula)	12
Family Members of women with fistula	9
Husbands of women with fistula	5
Professionals	23
Focus Groups	12

Table 1.1: Interview categories and quantities conducted during research period.

I also conducted participant observation in the clinics and home villages of women with fistula during all phases of this research project. Specifically, I spent time and conversed casually with research subjects in order to build trust and rapport, which, given the sensitivity of the topic, was essential to facilitating the disclosure of personal and sensitive information during interviews. In addition, observational data gained from participant observation enriched (and sometimes contradicted) what informants said during interviews and surveys with how they behaved, reacted, and conversed in an informal setting—thus, more accurately reflecting deeply-held attitudes and beliefs (demonstrated through conversational patterns and indicators of social distance, for example) which were integral to understanding the nuanced manifestations of fistula-stigma (the measurement of which is discussed in greater detail in chapter ten).

All interviews were conducted in French, Hausa, or Zarma. I translated all French interviews while Hausa interviews were largely translated into English by me, with help given from my research assistant (both at the time of the interview, and after to verify transcribed

direct quotes). As I do not speak Zarma, all interviews were first translated by a research assistant into French and then translated by me into English. Because of the two step translation process which risks amplifying dissonance from the original meaning, when possible, I attempted to paraphrase Zarma interviews. For specific quotes from Zarma, I relied on two research assistants to ensure the integrity of the original meanings.

The Challenges of Studying Incontinence

There is little research on fistula, and even less that is qualitative or that examines fistula's social consequences. This is largely due to the fact that obstetric fistula is notoriously difficult to study. Fistula is particularly challenging to study prospectively or longitudinally. Because there are no effective mechanisms by which women who will experience future obstetric complications can be identified (Hofmeyr et al. 2003; Vanneste et al. 2000), and even fewer means to identify which of those women with high risk pregnancies will develop a fistula (a relatively rare birthing injury), a prospective study of fistula is not feasible. And once women with fistula are retrospectively identified, longitudinal studies are rare, as the majority of patients are lost to follow-up, departing from clinics and returning home to remote and inaccessible villages, frequently far from roads or cell phone towers.

Additionally, the vast majority of fistula research is not done *in situ*, even if the object of study is a woman's social life back home; rather, it is conducted in clinical settings. Due to security concerns, my own research was not an exception, conducted mostly in fistula centers and only rarely in women's homes. Clinical settings are preferred because women with fistula are hard to access—the condition itself is relatively rare and it targets an already isolated

segment of the population.¹¹ Additionally, outside of a clinical context, fistula is a relatively unknown condition, even to village health specialists, particularly village healers (*boka*) or village surgeons (*wanzami*), who often conflate fistula with other gynecological abnormalities (see chapter eight).

Indeed, as some degree of incontinence can be caused by natural childbirth, several sexually transmitted diseases, or vaginal infections, studying fistula that has not been diagnosed within a biomedical clinical context is highly problematic. Most women in Niger (even when they have fistula—even when they have had it for many years) do not understand the biomedical concept of fistula (as a physical hole) or how it is different from incontinence (which may be a symptom of fistula, or entirely unrelated etiologies). Although fistula is biomedically defined by the abnormal anatomical connection between the vagina and bladder and/or rectum, no one but a clinician can diagnose the condition as such because it requires diagnostic equipment and training. For most lay people in Niger, fistula is defined entirely by its symptoms and conceptualized as a “sickness of urine” or “sickness of leaking urine.” Identified by the symptomology, studying fistula specifically rather than incontinence generally is not an easy task. Not infrequently did I speak with a woman who thought she had lived with the “sickness of urine” for several years (or sometimes decades) and recounted stories of mistreatment or reconfigured social networks due to her illness, only to find out after a biomedical clinical examination that she was diagnosed with a gynecological infection or incontinence due to other root problems, not an obstetric fistula.

¹¹ For example, see Murphy and Baba (1981) who followed women with fistula back to their villages in northern Nigeria. Although they selected 100 women to visit, 42 women lived more than 250km away and were eliminated. Of the remaining 58 women, 27 women were eliminated because their villages were inaccessible or could not be located. Due to difficulties locating women who had moved away, or could not be found, only 12 women were visited at home.

Other constraints to fistula research include the language barriers of researchers (of my sample of women with fistula, not a single woman could speak French, the official language of Niger), time constraints (a large proportion of fistula research is conducted by foreign researchers visiting clinics in the Global South for a period of days or weeks), and financial constraints (which often confines researchers to clinics where they can easily access many women, rather than traveling long distances to speak with only one woman in her home). Indeed, due to all of these constraints, the vast majority of existing fistula research is: 1) fistula-center based, 2) survey-based and quantitative—typically emanating from public health or clinical fields of research, and 3) conducted over short periods of time.

Due to political instability in the region at the time of my research, I was limited in the distance away from the capital the Nigerien Government allowed me to travel (and the amount of time I was permitted to stay in these locations). Due to this constraint, I was unable to study women in-depth in their homes. I was however able to follow several women who lived in or near the capital of Niamey back home on multiple occasions. This allowed me to cultivate relationships over time with their family members, husbands, and neighbors—often interviewing them, and observe women’s daily interactions outside of the clinical setting. This research aims to address to the methodological gaps in existing fistula studies—offering in-depth, qualitative *and* quantitative, extended research with this difficult to access population of women.

Exigencies on the Ground: Transforming the Project

I initially went into the field with the intention of following women through their surgical procedures and back home after surgeries in order to investigate if and how fistula-related stigma and post-surgical identities were negotiated by women themselves, their families, and local and

national stakeholders. My main questions were: Did stigma disappear once a woman's fistula was closed? To what extent were women's social relationships repaired along with their bodies?

However, once in the field, my project became infeasible for four reasons. First, women hide their fistulas within their communities. My presence alone could jeopardize a woman's identity passing as a well person (not to mention how ethically remiss and impractical interviewing her family members would be). Because fistula is presented by the media and donor agencies as stigmatizing—an all consuming, all defining trait—I had not previously considered the possibility that women's families and communities might not know. Previously published academic journals or popular articles did not discuss the topic or process of concealment. I had not considered the role concealment played in the lives of women with fistula (which will be discussed in chapter twelve).

Second, women—specifically those in Niamey centers—were not receiving surgeries. The women with fistula I interviewed in Niamey had stayed an average of seven months at their respective clinic, and as long as six years without having received an operation (see chapter two for further discussion). Only 61% of women in my sample received surgical intervention during my research period—of the remaining 39 women, 25 were actively seeking treatment.¹² Of the women who did receive surgeries, many of those interventions were unsuccessful, and so women stayed at centers, waiting for the next surgical attempt. So, by the time I had completed initial interviews, the majority of the women had not only not returned home, but many still had not received an operation.

¹² Of the 39 women who did not receive treatment, 15 women were still waiting for operations at Niamey fistula centers at the end of my research period, 9 women had returned home without receiving an operation, and one woman died of unrelated (although unknown) causes at the center. The remaining 14 women were not looking for surgery during the research period—2 women were treated non-surgically, 3 had been previously diagnosed as “incurable,” and the remaining 9 women had returned to centers for reasons unrelated to surgery (for example, trainings, treatment for other illnesses, or prophylactic C-Sections).

Third, when women ultimately did receive surgeries, their quest for continence was frequently far from over. Contrary to widely cited success rates, in my full sample, 44% of women had already undergone three or more previous failed surgeries (see chapter five for further discussion). I could not study the effects of a change if no change had occurred.¹³

Finally, I landed in Niger the day that French forces intervened into the neighboring country of Mali in order to combat al-Qaeda in the Islamic Maghreb affiliated groups that had taken over the northern regions. Instability and fear spilled through the porous border. Prison breaks, kidnappings, terrorist threats, suicide bombings, and the growing instability in the south due to Nigeria's terrorist organization Boko Haram who permeated Niger's southern borders, led to government restrictions of the movement of Westerners. At the beginning of my project, Westerners were no longer allowed to leave the capital without military escorts. Even if women with fistula were getting surgeries, even if those surgeries were successful, the restriction of my movements within rural areas impeded my ability to follow women back to their villages.

* * *

Anthropology is defined by fieldwork and ethnography. Our intimate knowledge of a place and its people, and the method by which we chose to engage with our site—ethnography—can circumvent the systems that control the flow of information, the bottleneck of what information gets out. Ethnography allows our subjects to speak, in their own voices. As anthropologists, our job is less to craft those voices into narratives that capture the realities of complex experiences and more to facilitate those voices being heard in their complexity and moral ambiguity.

¹³ I was, however, able to examine how fistula closure and restored continence affected women's lives by including in my sample women who were previously healed of fistula rather than attempting to prospectively study the phenomenon (although this approach also has its methodological weaknesses).

So, like many anthropologists, I spent my months navigating the flaws and challenges of the anthropological endeavor—the quest to balance objectivity and self-reflexivity within ever-shifting political realities of field sites. In the end, I strove to practice what Nancy Scheper-Hughes calls “good enough” ethnography, where within the limits imposed both by outside forces and internal struggles to reconcile the cultural self I brought with me to the field, I carefully and compassionately listened and observed (Scheper-Hughes 1992: 28). Here are the words of women in Niger as I heard them.

Chapter 2

Fistula Center Politics

From a distance, the political, economic, and highly personal forces that shape realities are blurred. Local conflicts, constraints, and controls are rendered invisible and replaced by generalities—assumptions of a pan-African (or even pan-Global South) experience of fistula. However, just as the experience of fistula in Niger is highly dependent on local context—on cultural expectations of marriage, womanhood, and fertility—the experience of treatment seeking cannot be disentangled from the highly charged political environment within which fistula care exists in Niger.

2.1 “Waiting” For Treatment

More than any other theme, “waiting” defined women’s treatment experience at fistula centers. During the period of my research, women with fistula who were seeking surgeries had stayed an average of six months (and a median of three months) at their respective center without having received an operation, ranging from two weeks to six years (see Figure 2.1). While no woman at the Danja Fistula Center had waited longer than three months, the same could not be said for the three fistula centers in Niamey. When the data from the DFC is removed from the calculations, the average amount of time that women had waited at centers for surgeries at the time of initial interview increased to seven months (and a median of four months).

When broken down by center, the averages varied dramatically: the average wait time at Danja was 2 months, ranging from 2 weeks to 3 months; Lamordé averaged 4.1 months, ranging from 2 weeks to 7 months; CNRFO averaged 5.2 months, ranging from 1 week to 2 years; while Dimol averaged 12.3 months, ranging from 2 weeks to 6 years. It is important to note that these

estimated wait times mark the amount of time from when a woman arrived at a center to my first interview with a woman, not her first surgery (which may have come many months later, if at all). Many women stayed at the centers throughout my research period and even after my departure from Niger, continuing to wait for surgeries.

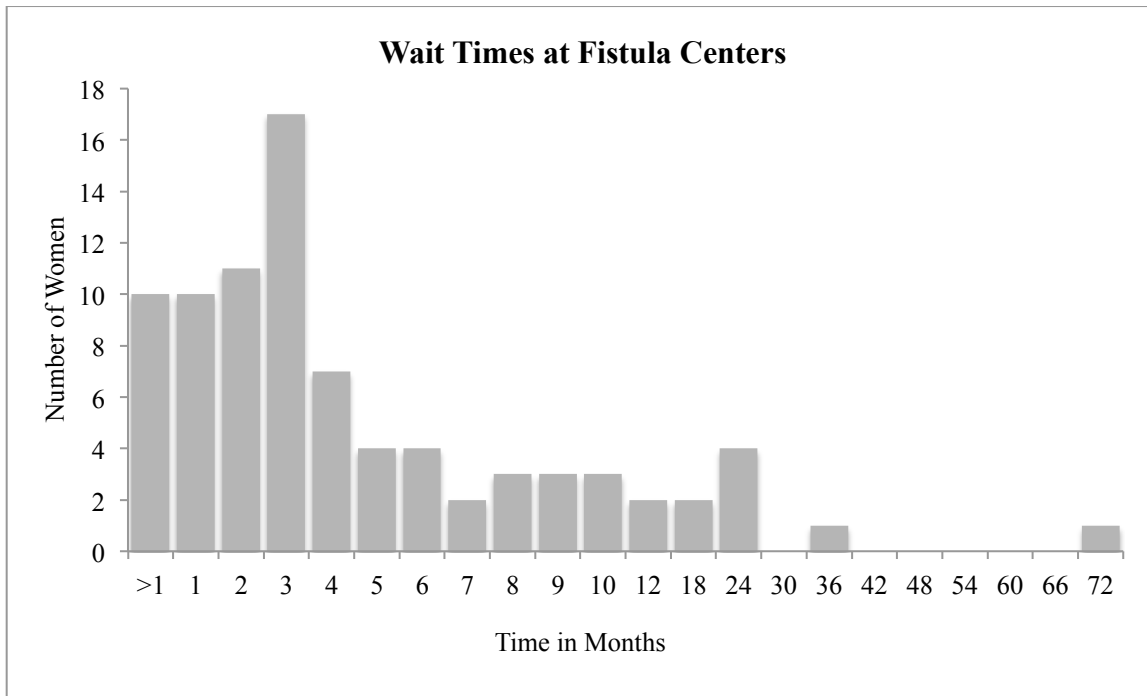


Figure 2.1: Time in months that 84 women seeking fistula surgeries had already waited at fistula centers at the time of initial interview. The average time waiting was six months, the median was three months, and the range was one week to six years. Two women seeking fistula surgeries did not know how long they had been at centers (and could or would not estimate), and their clinical intake forms could not be located, thus they were omitted from these calculations.

Although long wait times are not frequently reported on, some academic literature has discussed its prevalence and impact on women’s lives in Niger. In a study of fistula care in Niamey’s National Hospital (l’Hôpital National de Niamey, which stopped performing fistula surgeries in 2011), Ndiaye et al. (2009) described how long wait times compound social problems of dependence, stigmatization, and social rejection. According to another study conducted with 52 women with fistula at Niamey’s National Hospital, Harouna et al. (2001) also

remarked on the long wait times, noting that 45.5% of women had waited between six months to one year, while 34.5% had waited more than one year.

In an 18-month cohort study conducted with women with fistula in Niger and Mali, Maulet, Keita, and Macq (2013) investigate the prolonged and tortuous care-seeking episodes that women with fistula endure. They found that the median time spent in fistula centers during the study period was seven months and that stay duration was statistically shorter for patients who gained continence than for women who did not. Additionally, they found that nine women (all of whom had already undergone previously failed surgeries, 8 of the 9 were incontinent, and 2 of the 9 were deemed incurable) did not leave the center at all during the entirety of the 18-month study (Maulet, Keita, Macq 2013). These mobility patterns, the average wait times, as well as their findings regarding the significantly longer stays of women who cannot achieve continence, matched my own findings.

Interestingly, Maulet, Keita, and Macq (2013) seem surprised by their data, urging that, “Care duration of several months among new cases in our study deserves to be further investigated” (531). They add, “Getting rid of the preconceived idea that fistula repair comes down to one single short-lived care episode is a challenge. Indeed, after obstetric trauma and a stigmatizing journey, admission to a fistula repair center is seen as the near end of women’s pain and torment” (ibid.: 524). “It is assumed that fistula patients are either in the repair center before surgery or at home after it. Our analysis of care process duration and the resulting ‘patient wandering’ helps overcome this simplistic time and location dichotomy” (ibid.: 531).

During my time in Niger, it became clear that surgical repair is not a discrete event; it is a process, one which may take many years, and sometimes decades, several surgeries, an abundance of patience, and requires “patient wandering” and waiting through half a dozen to a

dozen fistula centers which may traverse regional, ethnic, and State borders. While Harouna et al. (2001), Ndiaye et al. (2009), and Maulet, Keita, and Macq (2013), all remark upon a similar trend of long wait times in Niger's fistula centers, my research builds upon these findings, suggesting that wait times may be substantially longer than previously recorded, and adding depth, nuance, and qualitative texture to understandings of waiting. The theme of waiting is woven throughout this dissertation—its effects marking women's lives as they navigate their bodies and social worlds marked by fistula, and factoring into the calculus of care seeking.

In general, fistula centers in Niamey had long backlogs, infrequent surgeries, high rates of surgical failure, and no protocol to address what to do with women whose fistulas could not be cured through surgical intervention (as a result, these women were kept waiting at centers until a better plan could be devised). As a result, a large roster of women waiting to be scheduled for operations populated Niamey fistula centers.

Of the 86 women who were seeking surgery, 25 women (29%) did not receive surgery during the year-long research period (while 61 women, or 71%, did) (see Figure 2.2). According to a UNFPA study reported on by Issoufou and Tassiou (2013), between 2009 and 2012, only 71% (2,205/3,122) of all identified cases of obstetric fistula were operated on, making the findings from my sample representative of Niger as a whole.

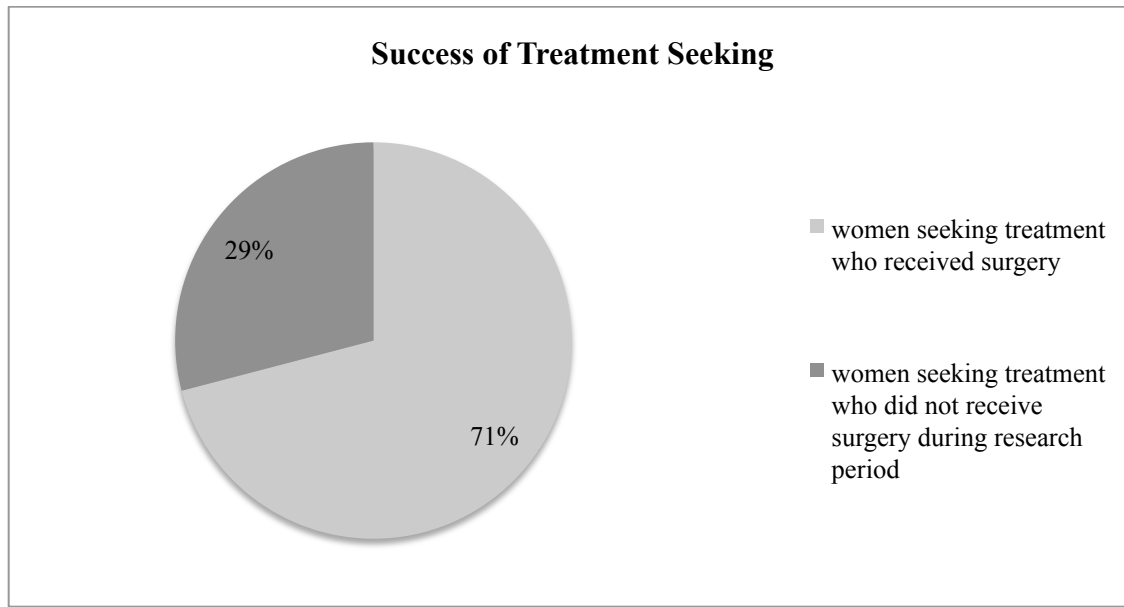


Figure 2.2: The success of treatment seeking of 86 women with fistula searching for operations. Sixty-one women (71%) of women looking for surgeries did receive surgery during the research period while 25 women (29%) did not. Fifteen women (17%) were still waiting for surgeries at the end of the research period, 9 women (10%) had returned home without receiving surgery, and 1 woman (1%) died at the center before receiving treatment.

One reason behind the long waits is due to the way surgical interventions are structured. Of my four research sites, only one (The Danja Fistula Center) was dedicated full-time to fistula repair, while one other (Dimol) offered women no surgical options at all. One center (Lamordé) operated on one or two women a week, and the fourth center (CNRFO) depended heavily on foreign surgical missions. As a result, many women became discouraged at centers, sometimes leaving before they received operations. For example, Abou, a fifty-year-old Hausa woman who had developed a fistula following her eighth pregnancy, had not undergone fistula surgery for the first thirteen years that she lived with fistula. She explained that she looked for treatment at various hospitals and was discouraged by the long waits:

I went to Maradi hospital and spent over a month there. Nothing happened. I didn't even see a doctor during the month I was there. Other women there had been waiting many months. I heard of a woman who had been waiting for four months without having seen a doctor. Some women said to me "Me I've been here one year" or "Me, I have waited here for three years." It was too discouraging. So, I just gave up and returned home.

While the findings of long wait periods and patient wandering are not uncommon for studies conducted in Niger, much of the fistula literature and the dominant media and donor narrative emanates from East Africa, and particularly Ethiopia where the largest, the first, and the most successful fistula centers dedicated to fistula repair surgeries—The Hamlin Hospital and their regional fistula hospitals—are found. Given Ethiopia’s sophisticated fistula care system, these long waits experienced by women in Niamey are unheard of, which may partially explain why waiting and wandering may not find their way into the dominant fistula narrative.

Because there is little to no discussion in the media or in donor reports of the long waits that women are frequently forced to accept at fistula centers, women who do not access surgery are often misunderstood. Women like Abou, who make an informed choice to return home rather than suffer through prolonged periods of separation from their communities, are rendered invisible. The assumption in some media representations is that these women are unable to access care, because they are “unaware” that a treatment for fistula exists or that this treatment is free. For example, the Society of Obstetricians and Gynecologists of Canada’s International Women’s Health Program explains that despite the affordability of fistula surgeries, many women do not access the procedure because of ignorance:

While most cases of obstetric fistula can be cured by surgical procedures costing approximately \$300-\$450, in the developing world, women with fistula may live their entire life with this preventable and treatable condition. Many are unaware that there is a cure and others simply don’t have the financial means or access to the procedure. (IWHP 2009)

Similarly, a news article regarding fistula in Uganda repeats this assumption:

Most women have fistulas for 15-20 years before they are able to have them repaired... But Nakolinzi says that outreach activities need to be tailored to women. The health ministry uses radio adverts to spread the news about fistula camps, but she says the message won’t reach those who need to hear it most. “Most people think they were cursed or bewitched or it was God’s will. People have never heard that it was [through] child birthing, they don’t know there is treatment ... We ask women who have had fistulas for

30 to 40 years and they say they didn't know at all that [repair] was happening. You need to reach down and send people there.” (Kardas-Nelson 2013)

Although I can not speak to the clinical context in Uganda, in Niger an understanding of the difficulties women endure once at centers, particularly the long wait times women are subjected to, may suggest another possibility: that some women know about the possibility of care but make the educated decision to stay home, preferring to live with chronic fistula than to endure years away from home (and the consequences that such an absence could have on their precarious social networks).

2.2 La Gratuité des Soins and The Price of Free Care

Early in the international movement to provide fistula care, public health officials, donor agencies, and clinicians understood that due to the unique demographic of women most at risk for fistula—poor, rural, and living far from treatment centers—even nominal fees could pose insurmountable barriers to care. As a result, all fistula centers in Niger (and nearly all fistula centers in the Global South) eliminated “user fees,” providing surgery, medicines,¹⁴ and room and board free of charge, referred to as “*la gratuité des soins*.”

Most centers also tried to provide women with transportation to and from the center (although not all centers in Niger were consistent in their ability to do so), hygiene products (such as soap), and small amounts of money or other goods attached to some sort of “reintegration” or “reinsertion” program upon a woman’s departure from the center (reintegration programs will be discussed further in chapter six). Often small donors attached themselves to the centers, regularly giving gifts to women including fabric, perfume, rice,

¹⁴ Fistula centers also provide for women’s health care while at the center, even if (or arguably for some centers, more effectively if) unrelated to fistula, most regularly providing women with medications for malaria, respiratory infections, and, as women tend to fall in showers (that are often paved or tiled, unlike the shower most women are accustomed to), broken bones.

sandals, money, henna, milk, sugar, tea, and other goods. Despite the complete “*prise en charge*,”¹⁵ or assumption of financial responsibility that centers assumed on behalf of women, women frequently complained of having no money, and thus feeling infantilized by centers. Women felt disempowered by their inability to buy snacks or meals from local purveyors when they were hungry, buy sandals when theirs broke, or otherwise provide for their own needs. As women could not farm at centers, they had very few opportunities to provide for even their most minimal needs or desires. Women complained that they had not foreseen the long periods of time that they would be expected to wait at centers, and thus had not come to centers with adequate financial resources to meet their quotidian needs.

Additionally, centers—particularly those in Niamey—were often unresponsive to women’s desire to leave the centers, sometimes withholding from women transportation money for the voyage home. Not infrequently, did centers not have the money to reimburse women’s transportation costs, or were the terms of transportation reimbursement inconsistent, often leaving women with large debts back home from bus tickets or taxi fare to the center that were purchased on local credit. Thus, despite the generous funding provided to fistula centers for the care of women, financial anxiety consumed many women during their time at the centers. For many center administrators, women were considered to have become greedy in their expectation of funding, refusing to pay any portion of their own care. Considering, however, how many surgeries many women were expected to undergo, and how many trips to and from the center such treatments required (which will be discussed in greater detail in chapter five), many women considered it impractical to contribute financially to their own care. This “free care,” which has

¹⁵ In an important contribution to the human rights of fistula patients, Lewis Wall (2014) proposes a “bill of rights for patients with obstetric fistula,” and among the seven-point list which includes such rights as the rights to dignity, competent care, privacy, the refusal of services or inclusion in research studies, self-determination, and informed consent, is, “the right to food, clothing, and shelter sufficient to sustain her basic needs while receiving care for her condition” (303). However, among the list, Wall does not specify the right to rapid care.

come to dominate donor narratives of fistula treatment, in the context of women’s lack of access to money, structured women’s relationship with the centers and with the marketplace around them. *La gratuité des soins* partially explains long wait times at centers where women are positioned as beneficiaries of “gifts” of care rather than clients of paid services with rights to demand high-quality, rapid interventions.

2.3 The Politics of Waiting

Both Lamordé and CNRFO claimed to offer a variety of programming for women while they waited, ranging from literacy classes to income generating activities training, sewing or weaving classes—the typical suite of “reintegration” or “reinsertion” program claimed to be offered by most fistula centers across sub-Saharan Africa and the Global South generally. However, the quotidian existence of women at the three centers in Niamey typically did not contain any scheduled programming and consisted mostly of sleeping, chatting with other women, praying or teaching each other/learning Quranic Suras, and beading bracelets. Sometimes women helped to cook or clean the center, braided one another’s hair, and focused on their own personal hygiene—spending much of the day washing themselves and their cloth, fastidiously avoiding the smell of urine. Still, women described their main activity at the center as “waiting” and “having patience.”

When at the center, very rarely did women venture far beyond the center’s walls, leaving only to purchase snacks at local purveyors in the neighborhood when they could cobble together enough money to do so, or for the women at the two abutting centers in Niamey, to visit one another. For women in Niamey, despite living in the country’s capital, their lives were not particularly urban as most had never been to any of the markets, nor to the city center. Most had explored beyond the centers’ suburban confines.

Just as there was very little social or educational programming, at all three Niamey sites, there was also very little medical programming due to a lack of resources such as skilled and willing medical personnel and other political constraints. At the centers, surgeries were infrequent (or, in Dimol’s case, did not happen at all), and thus so were medical examinations. Despite having the necessary resources to operate locally (with the exception of an anesthesiologist, whose availability—or lack thereof—was never clear), the administration at CNRFO demonstrated a preference for foreign surgical missions. There was some indication that this preference may have been due to financial incentives wherein foreign surgical teams would pay Nigerien staff for their participation in surgical missions, thus disincentivizing local staff to conduct operations independently. During the time that Lamordé was open and operating on women, Nigerien surgeons tended to operate on approximately two women with fistula a week. When surgical activities were stopped at Lamordé, it was with the intention to begin operating at CNRFO’s surgical block.

When the government took back the land where Dimol’s fistula center was located— and thus their buildings—in 2008, the Nigerien Government claimed that Dimol had mismanaged the center and rapidly reopened the center as the State-run CNRFO. Unsurprisingly, the Government and Dimol made radically different claims about what happened in 2008. Dimol claimed that the State was impressed by Dimol’s success and saw an opportunity to get into the “fistula market” as Dimol’s President Salamatou Traoré called it. Traoré and her staff at Dimol saw the State’s actions in 2008 as theft motivated by hopes of international acclaim and profit, as she told me that in the early 2000s international donors began funding fistula projects with large sums of money. Representatives of CNRFO claim that Dimol was poorly run and that the State acted on behalf of the women with fistula who were allegedly receiving poor quality services.

Almost as soon as the center was taken, the state began construction on a surgical block on the center's grounds, a calculated move that would later prevent Dimol from reclaiming the center even when courts ruled in their favor.¹⁶ Although the block was not functional until 2013, five years after construction began, it ensured that the center would remain in Government control. Mid-way through my fieldwork in 2013, fistula operations were stopped at Lamordé, and it was with the intention of opening an all-inclusive center at CNRFO (I speculate that this timing was to some degree motivated by a desire to compete with the Danja Fistula Center).

However, during the remainder of my field research there were no regular operations at CNRFO, and women only received operations every three to six months from foreign surgical missions. Even then, only a fraction of women at the center were operated on. These teams came from various countries such as Turkey, Sudan, or China, were often funded by those governments, by Islamic charities, or by the Saudi Arabian government, and typically arrived with one to two surgeons, an anesthesiologist, two to four surgical nurses, medical equipment, medications, and “bonus” or “incentive” money for local surgical teams.

After I left Danja to continue my fieldwork in the fistula centers in Niamey, when I would speak with administrators from Danja I would learn that they did not lack the capacity to operate. Their limiting factor was women. Due to both rumors regarding Christian proselytizing and systems of referral put in place in the capital that discouraged referring patients even in Maradi to Danja (only 12 km away), the Danja Fistula Center found its ward empty and its relatively inexperienced fistula surgeon unable to gain experience. While Niamey centers were awash in patients anxiously awaiting surgeries that never seemed to come, Danja had a surgeon, nurses, an anesthesiologist, medicines, and a full staff—but no patients. During my fieldwork I

¹⁶ In 2013, Niger appellate courts ruled that Dimol could take back the center only if they could repaying the State all costs associated with the construction of the surgical block—a massive sum.

came to understand that the politics surrounding fistula were toxic—fistula had caught the attention of Westerners and that meant it had also caught their wallets. Fistula meant money, and many important people wanted to corner the market. Certainly, good intentions, humanitarian interest, the Hippocratic oath, and quality programming were present. Yet, the dark side of fistula politics—where women were used as political pawns—all too often dominated the fistula scene in Niamey.

The politics of fistula in Niger are polarizing, blurred, and often women with fistula themselves are the victims of the morass. Information is power and it does not flow freely. Communication from funders to administrators often never makes it to center staff, and most certainly not to women. Indeed, very little information in the fistula clinics in Niamey is transferred to women themselves. They wait for months, and sometimes years, hoping for information, waiting for answers and praying for health.

During my months in Niamey, I spent a great deal of time focused on the question of why women were not receiving operations. I met willing staff after hours, away from the center's structures and inquisitive eyes and ears. Not infrequently did I feel more like an investigative reporter than an ethnographer. Trained as an anthropologist, but woefully unprepared for clandestine meetings and "off-the-record" divulgements, I struggled to distinguish when my digging was fueled more from indignation than pertinence to my research. Still, just as physicians take an oath to do good by their patients, anthropologists take an unspoken oath to understand and expose systems that prey upon and oppress the marginalized and vulnerable. I heard stories of political intrigue and accusations of mismanagement and corruption. Whatever the politics were, some individuals stood to gain, and although the contours of those politics

never became clear (or relevant) enough to write about with much depth here, what was clear is that it was never the women who stood to gain from those political maneuverings.

Women waited for longer than they should have; women were used as pawns in a political game, because in the fistula world, money was at stake. Much of what is written in this dissertation about the politics of international aid and the provision of fistula care can be generalized to sub-Saharan Africa or even the Global South. However, due to the particularities of the politics of fistula in Niamey, I write with this caveat: women's experiences with fistula in Niger are particular to a place and time. Many fistula centers around the world operate effectively and efficiently, drastically changing women's experiences seeking care. Throughout this dissertation, this spatial and temporal specificity should be kept in mind.

2.4 Philanthrocapitalism and Fistula Politics

Fistula politics in Niamey are to some degree the result of a larger transformation in international development and humanitarianism and global health—the emergence of “philanthrocapitalism,” or a market-based, business approach to development that prioritizes efficiency, effectiveness, performance goals, and (social) returns on investments (Desai and Kharas 2009; Marten and Witte 2008). This new generation of private donors is considered “more action-orientated, problem-focused and results-based than traditional donors” (Hailey 2011: 2). In turn, fundraising campaigns as well as development organizations more largely have been restructured, favoring specific projects with measurable direct impact rather than complex cross-cutting development agendas or governmental strategies whose impacts are hard to measure, systemic, and may take many years to yield visible results.

In the realm of global health, this translates into organizations focusing on disease-specific and technologically oriented interventions with measurable outcomes and reductionist

understandings of disease causality. According to Biehl and Petryna (2013), a multitude of actors vie for resources and influence, all seeking to remain relevant and powerful players in the rapidly evolving and competitive field of global health. In what Susan Reynolds Whyte calls a “projectified” landscape of care, “humanitarian schemes and health system building have made common cause with the technical and financial know-how of the private sector” (Biehl and Petryna 2013: 6).

For example, organizations such as World Vision allow donors to choose various gifts for poor families in the global South from a catalog, including \$100 for a goat and two chickens, \$96 for three ducks and a goat, or \$57 for three rabbits. Healing Hands for Haiti, which supports health care and rehabilitation medicine for Haitians, offers a donation menu ranging from \$1 to provide a pair of crutches to \$4,000 to sponsor a club foot surgery. The international non-profit Oxfam offers “Oxfam Unwrapped” catalogues where donors can choose to give money earmarked for various interventions, from \$12 for soap, \$20 for a mosquito bed net, \$150 to train a midwife, to \$5,000 to “help a village recover from a disaster.” The Fistula Foundation allows donors to enroll in the Love-A-Sister program, where \$50 provides an anesthetist for one woman’s surgery, \$240 provides transportation for twelve women in need of treatment, and \$450 fully funds one woman’s fistula surgery (the Fistula Foundation proudly claims that in 2012, 1,035 supporters donated through the Love-A-Sister program, raising \$314,732, and providing surgeries for 700 women). Indeed, the majority of international nonprofits’ websites now offer donors the opportunity to shop for interventions, where donors can (allegedly) give to specific interventions that donors feel best represents their personality, interest, or understanding of global need.

Philanthrocapitalism represents an evolution of, rather than a departure from, more traditional approaches to fundraising, such as the ubiquitous practice of child sponsorship which has been embraced by many (if not most) faith-based and secular NGOs working in the Global South for the past several decades.¹⁷ Child sponsorship, whereby a donor in the Global North would send money monthly (typically about a dollar a day) to a specific child who would in turn regularly send the donor letters and photos—ostensibly to demonstrate the transformative effects of the donor’s contributions for the child and his or her family, constituted the most lucrative fundraising tools of private donations for humanitarian assistance in the Global South (Smillie 1998). The relationships formed between donors and beneficiaries were generally hollow (in fact, many of the children’s letters were revealed to be written by field officers and most sponsorship agencies pooled donations at a national level which were then allocated to community projects, projects which did not necessarily affect individually sponsored children), and thus constituted an elaborate fundraising technique rather than the advertised comprehensive approach to development (Ove 2013). Still, through testimonials, a powerful technology of the self (Foucault 1997; Nguyen 2010), presenting a child’s image and personal story, donors were offered not only a way to effect change in a suffering child’s life, but transform themselves into ethical subjects. The success of such fundraising strategies may be embedded not in its potency at humanizing poverty, rather in the experience it offers sponsors themselves, “More than a fleeting feeling of compassionate warmth, child sponsorship offers (white) sponsors a way to become better people—a way to develop themselves as individuals while they help develop (black) Others” (Ove 2013: 27).

¹⁷ Child sponsorship programs began as early as 1938 through Save the Children and by the 1960s and 1970s became a ubiquitous fundraising strategy for various organizations involved in international humanitarian relief and development (see Ove 2013).

According to Hailey (2011), “Private donors are more targeted with their giving, and commonly focus on development challenges of special or personal interest... Generally they seem less concerned with issues that official donors [such as the United Nations or the World Bank] care about—for example, supporting good governance or enhancing security, or trying to ensure a balance between agricultural, educational and health funding.” Rather than addressing development with a holistic approach, the result is a balkanization of aid, whereby many nonprofits have organized to address a single condition (such as Operation Smile championing cleft palate repair, Nets For Life working against malaria, EYESee supporting vision correction through donated eyeglasses, or LEPROA backing leprosy interventions, among many others). These organizations’ continued existence depending on the sale of “their” ailment in a donor marketplace that rewards the confluence between high impact, cheap solutions for the most pressing problems.

However, this technocratic approach to development largely fails to address systemic structural impediments to development. Michael Edwards (2008) argues that “new loans, seeds and vaccines are certainly important, but there is no vaccine against the racism that denies land to ‘dalits’ (or so-called “untouchables”) in India, no technology that can deliver the public health infrastructure required to combat HIV, and no market that can re-order the dysfunctional relationships between different religions and other social groups that underpin violence and insecurity” (14). Arnove and Pinede (2007) argue that development organizations “claim to attack the roots causes of the ills of humanity; however they essentially engage in ameliorative practices to maintain social and economic systems that generate the very inequality and injustices they wish to correct” (389).

In examining efforts to eradicate malaria, Marcos Cueto (2013) argues that the international community has based health campaigns on three fundamentally flawed assumptions: that technocratic solutions can overcome obstacles posed by social conditions (whereby the malaria parasite and the mosquito carrier are considered the real problems and can be targeted through quick technological fixes such as insecticides and antimalarial drugs), that poverty is caused by disease (and not the other way around), and that technological interventions can only be managed by experts and thus interventions must be top-down. He suggests that international efforts to eradicate malaria have been historically ineffective due to their reliance on a deeply flawed premise of a “magic bullet” whereby “technological weapons aimed at defeating the threat of the malaria parasite and mosquito appear to be universally endorsed, while associated social, political, and cultural factors are downplayed” (2013: 50).

Additionally, philanthrocapitalism tends to bypass government structures and their presumed corruption, bureaucracy, and inefficiency, often favoring parallel, private development mechanisms seen as more efficient purveyors of aid and humanitarian relief. This approach further undermines the effectiveness of the public sector, often relocating even basic health initiatives outside the purview of the state (managed instead by international agencies and organizations) and funneling money into technocratic rather than systemic solutions. The role of government in the provision of basic health care for its population is redefined, reinforcing the structural inequalities and public sector deficiencies that often are ultimately to blame for organization’s pet causes. This form of intervention further inhibits holistic development focusing on systemic structural problems (in this marketplace of aid, few would choose from a catalogue to donate to large-scale efforts to decrease sources of standing water, for example), instead opting for more inexpensive, specific, and immediate interventions with tangible results

(like a bed net which results in the decreased susceptibility to malaria of one family—a family whose picture the donor may even receive).

* * *

In relation to fistula, philanthrocapitalism encourages interventions that are limited in scope (and required time and resources) and can be performed by non-state agents and organizations. Surgical intervention—thought to be quick, inexpensive, and highly effective—is championed, rather than systemic transformation of the basic infrastructure of maternal health provisioning.¹⁸ This philanthrocapitalistic environment is the political terrain within which fistula care is delivered, where fistula care is commoditized. Due to political constraints, conflicting personalities, and contested turf, the fistula world in Niger is defined by competition. Care is siloed, and fistula centers infrequently collaborate, instead competing against one another for limited resources. In the fervor of market-based approaches to health care delivery, women with fistula are too often neglected and deprioritized by the centers founded to serve them, waiting months or years for care.

¹⁸ There are notable exceptions to this statement. Many organizations work to address structural impediments to health. However, the philanthrocapitalist environment in which these organizations are forced to compete works to discourage these holistic and structural approaches.

Chapter 3

Profiles of Diversity:

Introducing The One Hundred Women

Although a total of 137 individuals were interviewed, including family members and husbands of women with fistula, as well as professionals working in fistula care, here I introduce the one hundred women with fistula who constituted the core of this research. Although I attempted to include a diverse range of voices, the sample was not universal and I asked women to participate based on a range of factors including my familiarity with a woman, linguistic limitations, and her desire to participate. In the beginning of my research, I chose women. I looked to include a diversity of ages and ethnicities. As is the case with many anthropologists, after some months, I no longer chose my informants—they chose themselves. The majority of women in my sample self-selected, this was particularly true in the sites where I spent the most time: Dimol and CNRFO.

As demonstrated below, the one hundred women who together make up my research sample converge in some important ways, representing homogeneity in educational attainment, rurality, and religion. However, these women also reflect marked diversity in ethnicity, geography, age, length of time living with fistula, and parity. Exploring the basic demographic profiles of the one hundred women who together compose my research sample—the ways in which they are similar and dissimilar—is essential to understanding the diversity in women's experiences living with and seeking treatment for fistula.

Key Characteristics of Research Sample			
	Fistula Centers		National
Region	Number of Women	Percent	Population by Region (DHS 2012)
Tilabéri	25	25%	16%
Niamey	4	4%	6%
Dosso	21	21%	12%
Tahoua	7	7%	19%
Maradi	23	23%	20%
Zinder	6	6%	21%
Agadez	1	1%	3%
Diffa	4	4%	3%
Nigeria	7	7%	
Mali	2	2%	

Ethnicity	Fistula Centers		National
	Number of Women	Percent	National Ethnic Representation
Hausa	41	41%	56%
Djerma/Songhai	31	31%	21%
Tuareg	14	14%	9%
Fulani	8	8%	9%
Kanuri	5	5%	5%
Other	1	1%	1%
Educational Attainment	Number of Women	Percent	Female Educational Attainment (Rural F.E.A.)
None	87	89%	80% (88%)
1-2 years	3		
3-4 years	3		
5-6 years	3	9%	11% (9%)
7- 8 years	2	2%	8% (3%)
Higher Ed.	0	0%	1% (0%)

Table 3.1: Key characteristics of research sample of 100 women with fistula, organized by region of origin, ethnicity, and educational attainment (and compared against national averages in Niger [DHS 2012]). Regionally, areas close to the four fistula centers were over-represented as compared to national population distributions (particularly the Tilabéri and Dosso regions near Niamey), whereas regions far from centers (such as Tahoua and Zinder) were under-represented in the sample. Ethnically, Hausa were under-represented while Zarma were over-represented as compared to the Nigerien population as a whole. Educationally, the women in the sample had very similar educational attainment composition as rural Nigerien women, but were less educated than Nigerien women as a whole. Only 98 women were calculated in the sample, as two women did not provide information regarding their educational attainment.

3.1 Ethnicity, Region, Education, and Religion

Compared to many West African countries, Niger is fairly ethnically homogenous, composed of seven main ethnic groups. According to the 2010 Nigerien Government census, the largest ethnic group in Niger is the Hausa, constituting more than half (56%) of Niger's population, followed by the Zarma, or the closely associated ethnic group, the Songhai (21% of the population). 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 of the country) while the Hausa regions are found in the east of Niger. The remainder of Nigerien people are nomadic, semi-nomadic, or historically nomadic pastoralists, including the Tuareg (primarily found in the

north of Niger) constituting 9% of Niger's population, the Fulani (dispersed throughout the country) 9% of the population, the Kanuri (found in the far east of the country) 5%, and the Toubou and Diffa Arabs (as well as other small minority groups) who together make up about 1% of Niger's remaining population. Of the 100 women with fistula that I interviewed, 41 were Hausa, 31 were Zarma or Songhai, 14 were Tuareg, 8 were Fulani, 5 Kanuri, and 1 was Mossinke from Mali.

Regionally, my sample came from across Niger: Tilabéri (25% in my sample vs. 16% nationally), Maradi (23% in my sample vs. 20% nationally), Dosso (21% in my sample vs. 12% nationally), Tahoua (7% in my sample vs. 19% nationally), Zinder (6% in my sample vs. 21% nationally), Niamey (4% in my sample vs. 6% nationally), Diffa (4% in my sample vs. 3% nationally), Agadez (1% in my sample vs. 3% nationally).

Regionally, areas close to the four fistula centers were over-represented in the sample as compared to national population distributions (particularly the Tilabéri and Dosso regions near Niamey—25 and 21% respectively in the sample, compared to 16 and 12% nationally), whereas regions far from centers were under-represented (such as Tahoua and Zinder—7 and 6% respectively in the sample, compared to 19 and 21% nationally). Ethnically, Hausa women were under-represented while Zarma were over-represented as compared to the Nigerien population as a whole (15% fewer Hausas and 10% more Zarmas than national ethnic representation).

Although I made efforts to purposively sample Hausa women (as I speak Hausa and do not speak Zarma), fistula centers in Niamey have a greater concentration of Zarma/Songhai women than Hausa women as Hausa women from Eastern regions of Niger often first go to regional hospitals in Diffa, Tahoua, Zinder, and Maradi for fistula treatment and are only referred to Niamey due to

complex cases, when operations fail, or due to individual connections in Niamey that facilitate easy referrals.¹⁹

Educationally, the women in the sample had very similar educational attainment composition as rural Nigerien women, but were less educated than Nigerien women as a whole. According to the Demographic and Health Surveys (2012), 80% of women in Niger (and 88% of rural women) have no education, while 11% (9% of rural women) have some primary education, and 8% (3% of rural women) have some secondary education. Nationally, only 0.7% of women (0.1% of rural women) have any education above secondary school. In my sample, no women attended more than eight years of schooling. Within my sample of 98 women, 87 women (89%) had no Western education (although many women had some Quranic education), while 3 women had 1-2 years of education, 3 had 3-4 years of education, and 3 had 5-6 years of education. An additional 2 women had attended between 7-8 years of Western education, although neither woman was able to communicate in French. None of the women in my research sample were literate nor could any speak more than a few words of French. Indeed, despite the diversity among women with fistula, as a whole, women with fistula in my sample had extremely low levels of educational attainment.

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%—98% of the population of Niger is Muslim (DHS Niger 2006; Meyer et al. 2007). Around 95% of Nigerien Muslims are Sunni, with the majority being linked to Sufi brotherhoods, while the remaining 5% are Shi'a. Of the 100 women interviewed in the sample, all identified as Muslim. I only interviewed three

¹⁹ Hausa women from eastern regions of Niger may cross national borders into Chad and Nigeria for fistula treatment. For many women in eastern Niger, traveling to northern Nigerian fistula clinics is often more appealing as these centers are Hausaphone (unlike Niamey centers located in a Zarma dominated region), may be located near family (as many Hausa Nigeriens migrate across the porous border), and are often much closer (and thus less expensive) to reach.

Christians, both of whom were professionals involved in provisioning care for women with fistula.

3.2 Reexamining Parity

Sixty-four percent of women in the sample experienced between two and twelve pregnancies, and developed a fistula following, on average, the third birth (see Figure 3.1). Also, among women in my sample, many pregnancies were conceived following the onset of fistula, offering a foil to the media and donor narrative that de-sexes women with fistula. While the media and donor narrative situates fistula as a disease of young, first-time (primiparous) mothers, who are left childless and infertile due to the injury (which will be explored further in Part I of this dissertation), the research data do not support this. For instance, a large-scale study of 2,484 women with fistula reported that only 31% of all fistulas occur during a woman's first pregnancy, while other studies have shown that only about half do (Broughton 2010; Hilton and Ward 1998; Mamane 2014). While just over half (55 women or 51%)²⁰ of women in my sample developed a fistula during their first pregnancies, the remainder of women who developed a fistula due to childbirth did so during their second to twelfth pregnancy.

²⁰ Although there were only 100 women in my sample, four women had recidivistic fistula (or two separate fistulas resulting from two separate deliveries) and three women did not develop a fistula due to labor (rather due to genital cutting, see chapter eight on *'dan guriya*). Thus, 51% is calculated by dividing 55 women by 107 total fistulas. If the three women whose fistulas were not the result of labor are excluded, first time pregnancies account for 53% (55/104) of fistulas.

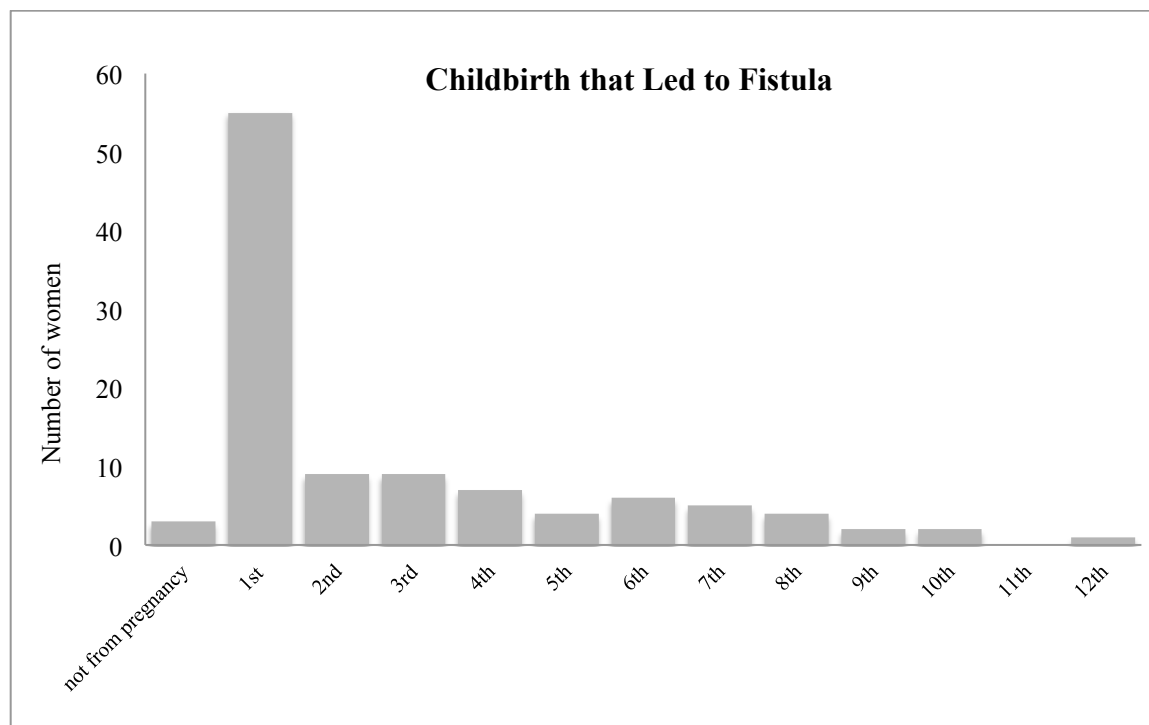


Figure 3.1: Pregnancy and delivery that led to fistula among 100 women (and 107 fistulas, counting 7 cases of recidivistic fistula). The average was the third pregnancy, but ranged from the first to the twelfth. Three women developed fistula due to non-birth-related causes.

In looking at the data from several studies, it is clear that these data are not unrepresentative. Roenneburg et al. (2006) state that, “Many caregivers have the impression that fistulas generally happen to primiparous patients. Our data indicate that at least one half of our patients were multiparous” (1751). Hilton and Ward’s (1998) study of 2,484 women with fistula in Nigeria found that 63% of women in their sample were multiparous. Landry et al. (2013) demonstrate that “for many, the fistula did not occur with a first pregnancy” (11). Bangser et al. (2011) conclude that “popular portrayals of women with fistula often depict young primiparous girls affected by the condition, yet our findings confirm data from other studies that demonstrate that fistulas happens to both younger and older women and all parities” (96). Amr’s (1998) study found that 71% of sufferers of obstetric fistula had five or more children, while only 5 out of 88 women (6%) were primiparous. Although individual studies frequently demonstrate that

women develop fistula throughout their reproductive lives, popular portrayals remain fixed on the woman with fistula as a first-time mother.

Additionally, although 55 (51%) women in the sample developed a fistula during their first pregnancies, only 34 (34%) women in the sample had experienced only one pregnancy (while 37 (37%) women experienced 2 to 5 pregnancies, 25 (25%) experienced 6 to 10 pregnancies, and 2 (2%) women had experienced 11 or 12 pregnancies), meaning that many women continued to have pregnancies (and thus engage in sexual activity) after the onset of their fistulas. This contradicts popular assumptions that de-sex women with fistula, demonstrating that many women continue to engage in sexual relationships while living with fistula. Indeed, although 55 (55%) women had no living children, 45 (45%) had between 1 and 6 living children.

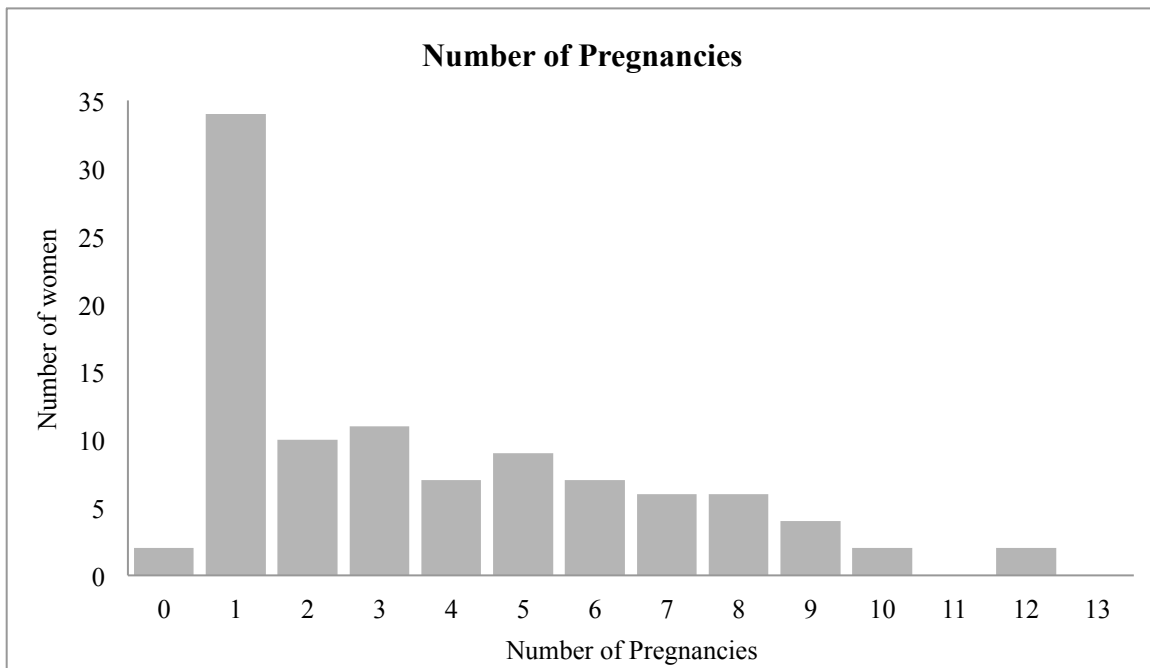


Figure 3.2: Number of pregnancies among 100 women with fistula. Women had an average of 3.7 pregnancies and a mode of 1 pregnancy.

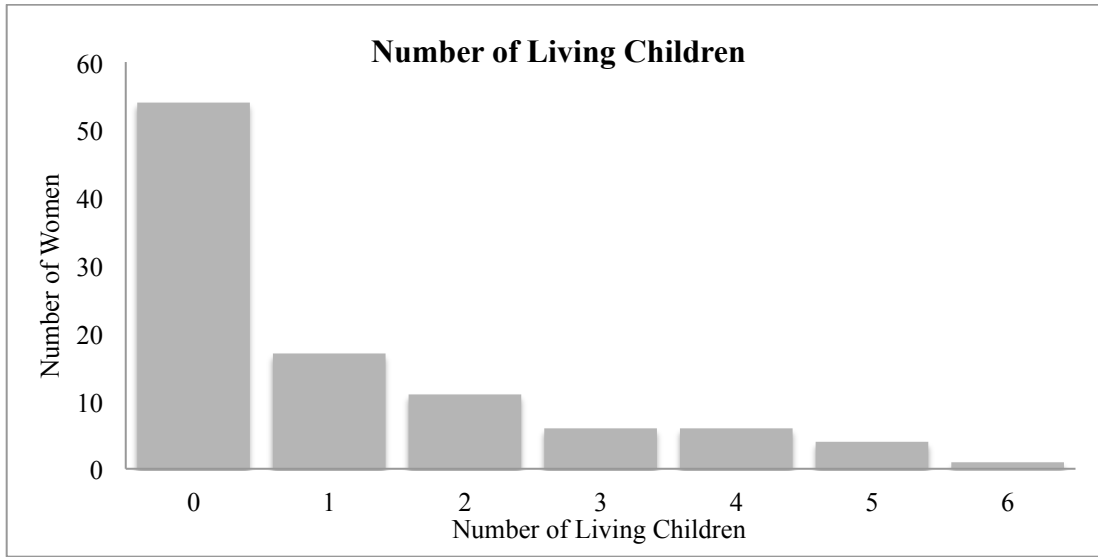


Figure 3.3: Number of living children among 99 women with fistula. The average was 1.1 and the median was 0.

3.3 The Diversity in Age

The women in my sample had an average estimated age of 31 ± 10.6 years, ranging between 15 to 70 years old (see Figure 3.4). Thirty-four percent of women were between 15-25 estimated years old at the time of interview, 41% were between 26-36, while the remaining 25% of women were between 37-70 estimated years old.

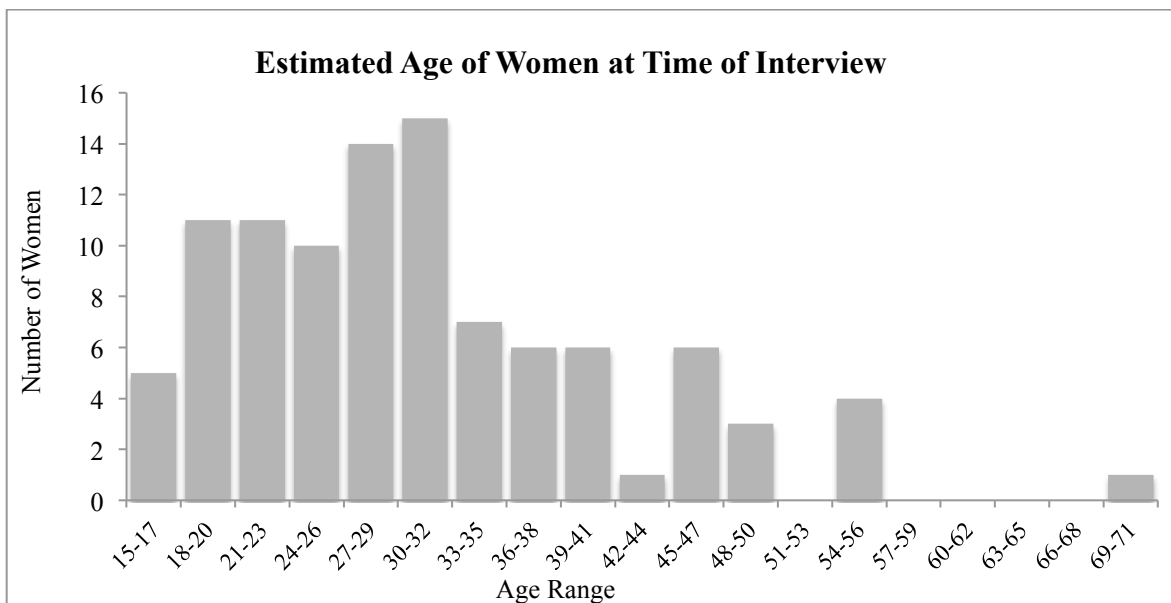


Figure 3.4: Estimated Age of 100 women with fistula at the time of initial interviews. The estimated average age was 31 ± 10.6 years, ranging between 15 to 70 years old.

Women developed fistula at an estimated average age of 23.5 ± 8.4 years, ranging from 13 to 54 years old (see Figure 3.5). Within this sample, women developed their fistula throughout their reproductive life spans, with 62% of women developing fistula between the estimated ages of 13-23 years old, 25% of women developing fistula between 24-34 years old, and 13% of women developing fistula between the ages of 35-54 years old.

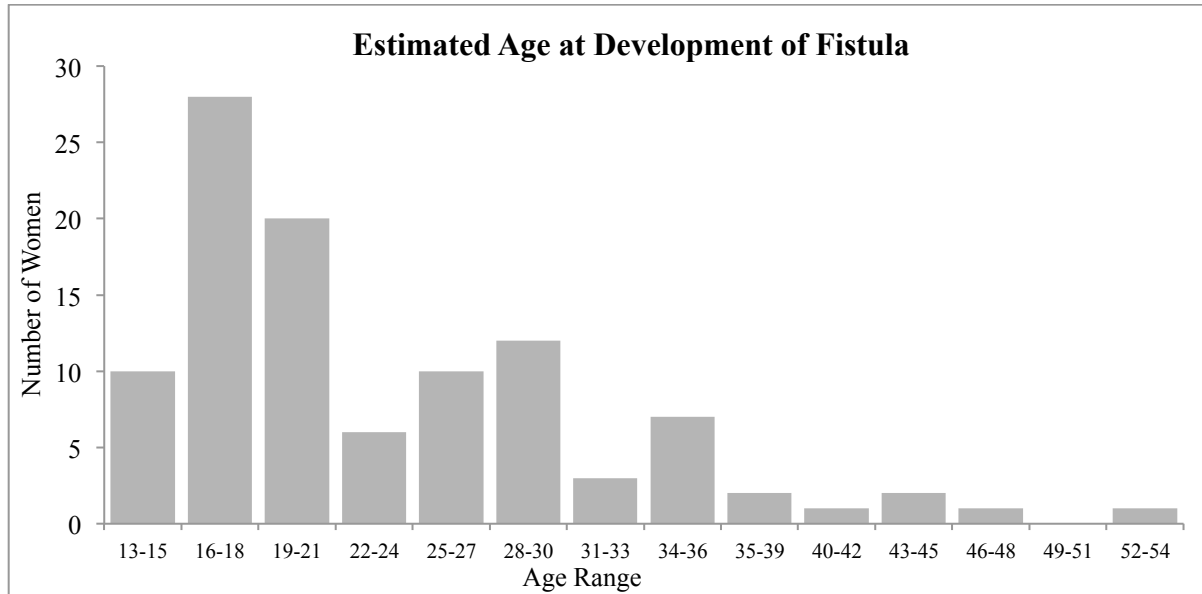


Figure 3.5: The estimated age at the development of fistula of 100 women. The estimated average age was 23.5 ± 8.4 years, ranging from 13 to 54 years old.

Years Living with Fistula

Sixty-four women lived with fistula between 0 to 5 years, 16 women lived with fistula between 5 to 10 years, and 18 women lived with fistula over 10 years (see Figure 3.6). The average amount of time women lived with fistula before I spoke with them was 7.6 years, ranging between 1 month and 50 years, demonstrating that women in my sample represented a vast range of experience.

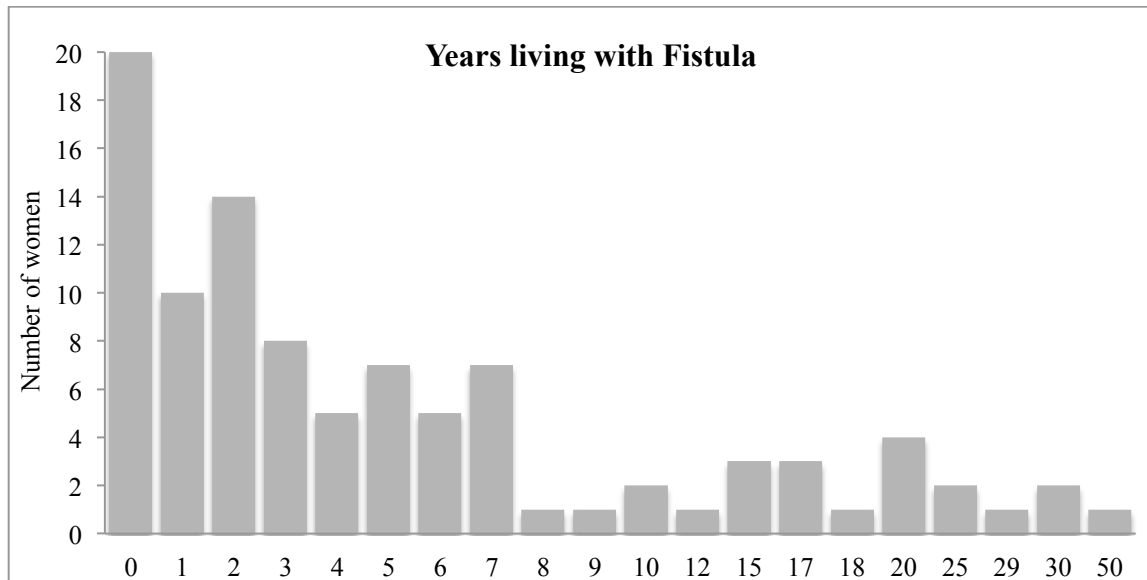


Figure 3.6: Duration in years that 98 women lived with fistula at the time of initial interviews. The average was 7.6 ± 8.6 years, ranging between one month and 50 years.

In speaking about my findings with some scholars, clinicians, and humanitarians who work with fistula, I have experienced some resistance. A common criticism that I hear, particularly when speaking about the diversity in experience of fistula-stigma (which will be discussed in Part III of this dissertation) is, “But what about the women who are too stigmatized to seek care?” The concern seems to suggest that there are two discrete groups—that women who are seeking care are distinct from women who are “hidden” at home and not seeking care. Based on the experience of women in my sample, I believe that this is unlikely. Women in my sample who have lived with fistula for 50 years, 30 years, 25 years, 15 years, or 10 years all have experience with both extended periods of treatment seeking as well as extended periods at home, when they have opted out of biomedical care. Although there are women who are still hidden, these 100 women can tell us something about women who have not made it to fistula centers and their experiences.

A Note on the Triangulation of Age

Scrawled in the corner of a notebook, jotted down during a particularly difficult segment of an interview—a confusing and drawn-out reconstruction of years—is a fieldnote: “piecing together a chronology is a painful process. I am taking leaps, cobbling together what will certainly—but once I’ve left the field, unfalsifiably—be, to some extent, a fabrication.” On another day, I note:

I feel like a detective much of the time, trying to put together timelines, deciphering things said out of shame or fatigue or frustration from the truth. Nine months in between interviewing this woman, she apparently has aged a decade. I push and prod until I arrive at a truthful, coherent narrative. But still, no one knows if I fail. Not even me. How much of what I write is a half-fiction?

In rural Niger most people do not prioritize tracking their or their children’s ages thus may not report it accurately or consistently. However, because so much emphasis has been placed on the extremely young ages of women with fistula my media and donor narratives, I found that accounting for the ages of women in my sample, and attempting to note the ages of their first marriage and first pregnancies, was essential.

When presenting final data, grouped in charts and presented in tables, quantitative measurements such as ages (or for that matter any numerical measurement such as numbers of pregnancies, number of previous surgeries, or months waiting for treatment) gives an air of empiricism. However, unless researchers have access to national identity cards or certificates of birth, they must rely on their informants’ ability to accurately recall and self-report these facts. I often found myself frustrated by arithmetic that did not add up. Once a woman who appeared to be in her late 50s or early 60s shrugged when I asked her how old she was, replying, “I couldn’t say. About 30.”

But often, only a dozen or half-a-dozen years were unaccounted for. One young Zarma woman explained to me:

I am 22 years. I was married at 15... I waited 6 years before my first pregnancy. I had 3 pregnancies... My one living child is 6 years old... I got fistula during my 3rd pregnancy.

In my head I quickly did the math: $15+6 = 21 + 9 \text{ months} = \text{about } 22$. $22 + 6 = 28$, not 22. In situations like this one, I gave priority to how many years the woman had lived with fistula, and how old her children were, as those ages were probably more accurate than more distant ages (like age at marriage). When numbers failed to add up, I tended to work backwards.²¹ For the woman above, she seemed confident that she waited six years after marriage before becoming pregnant—because this was an unusually long period of time to wait, she remembered distinctly those six years, so that made her between 21 and 22 at her first birth. Since her oldest child was 6 at the time of the interview, I assumed that she was closer to 27 or 28 than 22 years old.

Through triangulation, I found that women often under-estimated their ages. Taken at face value, women might come across as even younger—which is perhaps in the interests of certain donor or media narratives.

I include this not to delve into an epistemological *cul-de-sac*, but as a cautionary reminder because we all—anthropologists included—rely on numbers as proxies for larger truths and greater meanings. Here I suggest that we keep in mind that despite the fact that my informants and I arrived at an age, that age is a construction—the end point of a negotiation rather than a “truth.”

²¹ This method is similar to what Murphy (1981) used when working with women with fistula in northern Nigeria, where, “Because of probably inaccuracy of age as reported by the subjects, the state age at first attendance and at marriage were checked against duration of marriage, duration of marriage before the respondent became pregnant, length of time after marriage that menstruation started, and length of time between developing a fistula and seeking treatment at Zaria hospital, and adjustments were made for any inconsistency” (140).

Potential Sources of Bias in the Research Sample

Because the sample was not universal nor was it random, it is possible that I over-sampled women with chronic, complex fistula. As women with difficult to repair fistula were often at centers longer than women with relatively straight-forward presentations, women with complex fistula may have had more time to become comfortable with and trusting of me, and thus more likely to accept (or even propose) an interview. Also, as women with complex fistula tend to be older, cultural norms surrounding shame and propriety, which are particularly salient for younger women, may not have served as such a barrier for older women in discussing the sensitive interview material. That said, of the women I asked to interview, only a handful refused interviews (and they represented a diversity in age and fistula complexity). Although I made efforts to be aware of this bias, and included women who arrived more recently and who had more straightforward fistulas, it is important to note that this bias may have affected the sample composition.

* * *

The women in my sample reflect diversity in ethnicity, geography, age, length of time living with fistula, and parity. Now, with some basic ideas about who these women are—where they come from, how old they are, their educational and reproductive histories—we can move forward and examine in Part I how this diverse of group of women is translated and distilled into a single sufferer by a global fistula narrative that flattens diversity of experience in an effort to make fistula, and its victims, eminently recognizable.

PART I:

THE GLOBAL FISTULA NARRATIVE

Sadata's Story: The Other Extreme

Fistula has become symbolic of the physical consequences of harmful culture on the quintessentially innocent. Donor agencies and the global media that generate and circulate the narrative of a monolithic (often young and agentless) sufferer do so to bring resources and attention to women with fistula—aims that I share. However, my experiences in the field complicate this narrative of a single sufferer. As I parsed together story after story of Nigerian women seeking treatment for obstetric fistula, neither archetypical sufferers nor archetypical stories of suffering emerged. Women's stories are as diverse as they are—they are young and they are old, they are rejected and they are embraced, they are forced by parents to marry before menarche and it is they who choose when to marry the men they love.

Still, the discourse surrounding obstetric fistula presents an archetypical narrative—a single woman. She is just a girl really. One by one, she is abandoned by her husband, then her community, then her family, until she is alone. She is ridiculed, poor, and hungry. She is enshrouded by the indelible odor of urine or feces. And yet, out of the one hundred women with fistula who I have interviewed, and the dozens more with whom I have informally chatted, I can count on one hand the few who fit this bill. The archetypical fistula sufferer—young, abandoned, and crippled by shame—exists. She is just at the far end of a multidimensional spectrum.

If I placed the women I met on a spectrum, the stories from the extreme ends are interesting, real, but not accurate reflections of the majority of women who find themselves somewhere in the middle. In relief to the young girls who populate organizations' pamphlets and reporters' columns, here is the story of a woman who deviates from the norm as much as these abject few. She is the other extreme:

I met Sadata at a Niamey fistula center. Just two weeks prior, Sadata’s catheter was removed, and as she whispered over and over “*Alhamdulillah*,” praise to God, not a drop of urine fell. After a yearlong search for continence, Sadata had arrived.

Sadata was married at 20 years old to the man of her choosing. “*Soyayya muke*,” it was mutual love between them, she told me. He was her first cousin, and rather than bring her problems as *auren gida*, or intra-family marriage, does for many other women in the face of reproductive complications, she explained to me that because her husband was her family, and her mother-in-law was her aunt, they had no choice but to support her, love her, and have patience until God saw her through. And they had. She said that through her sickness, her husband never said a bad word towards her, he refused her nothing, he never took another wife, and he waited patiently during a year of abstinence while she lived with a catheter.

Sadata developed a fistula during her fourth pregnancy. At a prenatal consultation she was told that her child had a deformation, an enlarged head that could make a natural birth difficult if not impossible. As soon as her labor began, her husband rented a taxi (with money he had saved up since he heard the news of potential complications). By the time she arrived at a health center, she had birthed the hands and feet of her child, but as expected, she was unable to birth his head. The nurse reported that the child had already died, but because the center was not equipped to perform Cesarean Sections, he pulled with extreme force to extract the body.

Soon after, urine began dripping down her legs, but because she had never heard of any sickness that rendered a woman incontinent, she went home and tried to wait it out. Eventually, through a long and convoluted chain of referrals and misdiagnoses, she arrived at a fistula center. Due to a long backlog for surgeries, and political tensions which make fistula repair surgery unattainable for many women, the center opted to try an older technique—inserting a catheter for

a prolonged period, hoping that the respite of urine leaking on the raw tissue in the vagina would allow the hole to heal on its own.

Sadata lived with the catheter, which connected to a small bag to collect her urine, for eight months. Because she lived close to the center in Niamey, she spent most of those eight months at home with her family, returning to the center once a week for a check-up. She told me that while the catheter was physically uncomfortable, and while she worried that it would not fix her fistula, she never experienced any mistreatment from anyone. No one refused to eat the food she prepared. No one called her names. No one spit when she passed. Life went on. And because there was no vast distance between her home and the fistula center, during her year of treatment she spent every night at home with her family. Sadata did not suffer from the prolonged absence usually required of women seeking treatment for fistula.

You will see, she said. “Come home with me, and you will see. My family will be there waiting. They will say ‘Sadata is home! Thank God, Sadata is back!’” Curious, and wondering if perhaps she was withholding experiences of mistreatment, I took up her offer (which may have been more for rhetorical purposes than an actual invitation, but such awkward impositions are standard—and arguably necessary—for anthropological fieldwork).

When we passed through the mud archway of her home, pushing aside the woven grass mat that acted as a door, her sister ran to us. Her twelve-year-old daughter flung her arms around Sadata’s waist. They ushered us into a small room with mats on the floor—the only room of the house. Her husband came in grinning. Her four-month-old niece was placed in her arms. Her father, who reclined in the shade, beckoned us. I spent the afternoon sitting with her family—listening in as they joked, laughed, gossiped, and told stories and parables.

Even if beyond that placid afternoon, Sadata's neighbors did gossip about her condition, or her friendships did suffer, the truth remained that Sadata's experiences of fistula were equal parts suffering and frustration as social support and compassion.

And indeed, if we accept only one fistula narrative, denying that for some, illness does not disintegrate social networks, rather it reinforces them, then we cannot understand what makes Sadata different from women all the way at the other end of the spectrum. Can it all be boiled down to luck, or is there some confluence of factors (age? parity? ethnic group? severity of fistula? conjugal dynamics? length of time away from family?) that predictably determine where on this spectrum a certain woman will fall?

When I hear various manifestations of the global fistula narrative, my first instinct is to question my data. Why are the stories I have heard so different from these stories? But then I recall that perhaps they are not so different in content. One woman told me how she often thought things would be better if she were not alive. Another woman told me how she attempted to slice off her entire vagina with a straight razor—frustrated by her genitals and how they had caused her nothing but problems. Still, these stories were in context. They were points that punctuated a life narrative, a narrative consisting of both highs and lows. The same woman who told me about suicidal thoughts also recalled stories of warmth and care from her friends and neighbors. The woman who had attempted to slice away her leaking vagina also told me of the sacrifices made by her father, uncles, and brother to find her care. Perhaps the stories that populate the fistula narrative are not untrue, they simply are not contextualized within a rich a varied life experience.

Without understanding exactly why some women are unlucky enough to find themselves rejected and mistreated in the face of fistula, while others find themselves embraced and cared for, it is important to remember that most women find themselves somewhere in the middle.

So, if we begin to look at the middle of the spectrum for a new fistula narrative, what is it? What ties these women together? Seeking care in a world of disparities and structural inequalities, feeling the shame and frustration that comes from adult incontinence? And what can anthropologists pass on to clinicians to encourage more experiences like Sadata's and fewer from the other extreme?

In Part I, the three chapters that follow explore the narrative constructed around obstetric fistula, crafted and reproduced by donor organizations and the media. Chapter four examines how and why the narrative was constructed. Chapter five investigates how modest surgical outcome data are massaged in order to fit into the fistula narrative's claim of high surgical success. Chapter six considers both the conceptual and concrete costs and consequences of this fistula narrative.

Chapter 4

The Fistula Narrative and The Marketplace of Victimhood

On 23 May 2013, commemorating the tenth anniversary of the United Nations Population Fund “Campaign to End Fistula,” CNN reported that women afflicted with obstetric fistula faced “a fate worse than death” (Winsor 2013). The tone of the article was of condemnation and anger, directed at the social suffering that allegedly marks the fate of every victim of obstetric fistula. “A woman with fistula, who is perpetually leaking urine and sometimes feces, is often rejected by her husband and shunned by her village because of her foul smell and her inability to bear more children” (Winsor 2013). The CNN piece asserted, following a well-rehearsed formula, nearly identical to stories told by other media channels on that day, and on the days, months, and years before (and similar to the Kristof piece presented in the introduction). The ingredients of this formula consist of an array of conspiring elements, all of which are routinely integrated in most popular and academic discussions of the condition: fistula sufferers are young girls forced into “child” marriages; due to their youth, potential malnutrition, small stature, and lack of negotiating power within their households, these girls suffer through a complicated labor for up to a week without any medical intervention; following the onset of their postpartum incontinence, they are abandoned by their kin and exiled from their communities; barely surviving, they eventually find redemption in a life-changing surgery that restores their continence and enables their return to the fold of society.

At first glance, this narrative does not appear especially problematic. It speaks to a humanitarian-minded Western audience; it inspires sympathy and action. Alarmed celebrities,

journalists, international aid workers, and feminist scholars—along with a galvanized public—have all been mobilized in the fight against fistula, lending credence to the narrative and helping to circulate it.

Anthropologists have long problematized representational practices of international non-governmental organizations (NGOs), which have variously been accused of commodifying images of faraway suffering, erasing local voices, and dehistoricizing indigenous accounts (see for example Butt 2002; James 2010; Fassin 2012; Kleinman et al. 1997; Malkki 1996). Within this vast corpus of development and humanitarianism critiques, humanitarian action is thought to perpetuate asymmetrical power relationships, contributing to the “humanitarian reduction of the victim” as a passive recipient of aid (Fassin 2007). Silenced by carefully packaged coverage, generalizations, and assumptions about naturalized states of violence and depravity in African and other resource poor communities around the globe, victims are rendered mute, ahistorical actors—a synecdoche for all of the ravaged Global South. In many ways, the fistula story symbolizes the apogee of these portrayals. It represents what I call “superlative suffering.”

Humanitarian organizations compete for donors and reporters compete for readers, and in an attempt to rouse the public from a “compassion fatigue” stupor (borrowing Susan Moeller’s terminology), victims are presented as more and more pitiable, and solutions as ever quicker, easier, and more effective. A formulaic representation of far away suffering employs sensationalized language, metaphors of war and ravage, and powerful images of the wretched, stripping sufferers of context and nuance while situating actors in the prescribed roles of victim, villain, and redeemer.

For a story to gain public traction in the Global North (specifically the West), the requisite threshold of suffering is ever rising, and depictions of human suffering are replaced by

the superlative, because, as sociologist Stanley Cohen puts it, “like the tolerance effect produced by heroin addiction—the syndrome of compassion fatigue needs a stronger antidote each time” (Cohen 1999: 590). A hungry child will no longer open wallets or capture readers’ attention—now the child must be on the verge of death (recall Kevin Carter’s Pulitzer Prize winning photograph of a vulture stalking a Sudanese toddler who had collapsed from hunger; see Kleinman and Kleinman 1996). An abused woman no longer merits attention—now she must be the victim of savage, rifle gang rape. Girl children oppressed by regimes of patriarchy are rendered invisible until they are disfigured by acid attacks or close-range gunshots from the Colt .45 of an indurate terrorist.²² Fistula is competing intensely in this marketplace of victimhood, having pulled ahead in the “race-to-the-bottom” of suffering.

The fistula formula has become an NGO trademark of sorts, as it now comes as a pre-packaged story whose elements hardly vary—even across vastly different countries and contexts—and which can be widely consumed, especially at a distance. Although individual scholars have contradicted some main tenets of this narrative—often one piece at a time (see for example Landry et al. 2013; Maulet et al. 2013; Mselle et al. 2011), the fistula brand remains fairly constant across various forms of media and organizations championing the cause. This branding has succeeded in building up a consistent, iconic profile of the fistula sufferer over time. The fistula brand presents a single imaginary of the girl with fistula, one that is both emblematic and generative of social crisis. This brand does not exist in a vacuum, of course, as its general contours are in line with pre-existing images of crisis-ridden (rural) Africa, steeped—as it continues to be seen by many—in tradition and dysfunction (see Comaroff 2007). This familiar engagement identifies unenlightened culture as a harmful societal force that enslaves

²² Here I reference the widely covered attack of Malala Yousafzai, a Pakistani girl who was shot in the hand, arm, and face by a member of the Taliban due to her outspoken support of girls’ rights to education.

women's bodies to "tradition," seen in turn as a formidable obstacle that blocks a country's pathway to health and development. Writing about the British colonial period in East and Central Africa, Megan Vaughan (1991) notes how the language of cultural difference as a causal factor for disease steadily supplanted a focus on economic and environmental causes. This medical discourse, she writes, assigned blame for disease to culture: "Susceptibility to disease in Africans, then, was defined not through an analysis of the conditions under which they lived and worked...but rather through the idea that the cultural practices of different ethnic groups disposed them to various disease patterns" (46).

The idea of culture as a culprit for illness and mortality finds its contemporary expression in the notion of "harmful traditional practices." As global NGOs are increasingly becoming the principal agents for policing biomedical standards worldwide, this idiom has come to dominate many of their public health initiatives, especially in Africa and Asia. This discourse is highly gendered, with an almost exclusive focus on the victimized bodies of women and girls, and, complementarily, with blame placed on the shoulders of brown-skinned men. And as during colonial times, an international audience has been galvanized into expressions of outrage over cultural norms that are seen to compromise female reproductive abilities in particular.

Narratives about cultural—rather than medical, socio-economic, or political—failure reinforce assumptions of African inferiority and inadequacy. Popular appeals of why women with fistula need salvation repeat discursive presentations of Africa lying "in her blood" from an earlier era (Comaroff and Comaroff 1997; see also Hunt 1999; Vaughan 1991), thus justifying the need for Western intervention.

4.1 Cultural Interventions and Moral Crusades

Campaigns to eradicate fistula have effectively reinstated earlier calls to save African women—often from their own husbands and cultures—that have prevailed since periods of colonial intervention and have often served as justification for imperialism. These colonial (and post-colonial) representations of Africa reified male domination as “traditional” while ignoring the ways in which colonial intervention and economic transformation affected gender systems and oppressed both men and women of the Global South. This framing of hegemonic patriarchy and female subjugation has drawn heavily upon popular and historically embedded Western suspicions of “African culture” and religion, particularly the subjugation of African women and children through “child” marriage, wife seclusion, polygamy, and veiling, among other practices.²³

During the past forty years, international interest has focused in on women and children in the Global South. The United Nations declared 1976-1985 the Decade for Women, channeling funds into projects earmarked for women’s rights, health, and empowerment. Soon after, 1989 marked the United Nations Convention on the Rights of the Child, heralding the 1990s, a decade that marked an impressive world-wide interest in both women’s and children’s issues. Some argue that fueling this enthusiasm for the rights of women and children was an underlying moral panic that consumed the Western world (see Boyden 1997; Hart 2006). Drawing from a labeling theory perspective, moral panics refer to societal response to beliefs about a threat from moral deviants and may be recognized by their volatility (a sudden eruption and subsiding concern regarding a newly perceived threat to society), hostility (deviants are regarded as enemies of society’s basic values), measurable concern (concern about the threat can

²³ Western condemnation of culture or tradition in the Global South is not limited to Africa. Discourse that indicts “culture” or “tradition” in the development of fistula in Africa resembles discourse surrounding *sati* (widow-burning) in India, footbinding in China, or veiling and *purdah* (wife seclusion) in Islamic societies.

be measured through, for example, surveys), consensus, and disproportionality (the perceived threat is greater than the actual threat) (see Victor 1998). Building upon a Foucauldian understanding of modern sexuality in which sexuality is thought to be inherently political and entangled in relationships of power, Deborah Posel (2005) argues that episodes of politicized sexuality “illuminate in unusually vivid ways how the discursive constitution of sexuality is enmeshed within a wider matrix of moral anxiety, social instability and political contestation” (241). Unsurprisingly, issues surrounding sexuality, gender, and thus power, both domestically and abroad, provide fertile ground for moral panics and political contestation.

Western interest and intervention into fistula can be viewed as a *cause célèbre du jour*—the most recent of a long line of cultural interventions, reflecting Western interest in passive female sexuality, male culpability, and Western biomedical/cultural potency in the Global South. The rhetoric surrounding obstetric fistula closely mirrors the discourse surrounding sex trafficking and female genital cutting in the Global South. In the discourse surrounding all three of these moral panics, women of the Global South come to be seen as ill-treated—but passive—entities whose bodies do not belong to them but rather to their malevolent male kin.

Female genital cutting (or what the global media and Western public commonly call female genital mutilation, or FGM) became a popular topic of Western interest and intervention beginning in the 1970s and climaxing in the 1990s and 2000s (see Boddy 1996; Obermeyer 1999). A review of the literature performed by Google scholar retrieved only 33 articles about “female genital mutilation” written in 1970 to 1980, which increased to 143 the following decade, then 2,905 in 1990 to 2000, 10,890 between the years of 2000 and 2009, and 9,830 between 2010-2014. (see Figure 4.1; The graph illustrates that FGM became a popular topic of discussion circa 1990).

Among others, some Western scholars concerned with human rights and feminist politics have treated both female genital cutting and fistula as a somaticized metaphor for cultural cruelty, heeding the call to arms in this revitalized war on culture. According to Walley (1997), beginning in the 1970s, Second Wave feminists in the United States and Europe began condemning FGM, in the process characterizing African women as “thoroughly oppressed victims of patriarchy, ignorance, or both, not as social actors in their own right” and thus focusing exclusively on “the tormenting of girls, if not solely by men, then by a monolithic patriarchy” (419, 418). In the Western feminist movement the clitoris had become a metaphor for women’s power and self-determination, and thus, through its excision, female genital cutting became a particularly graphic (and thus effective) symbol used to highlight women’s oppression. By the 1980s, female genital cutting was labeled by scholars—including many anthropologists—as a “crime of gender,” “torture,” “barbarism,” and “ritualized torturous abuse” (Lane and Rubinstein 1996). In the 1980s and 1990s, even many anthropologists—heretofore associated with cultural relativism—believed female genital cutting could be “clearly condemned as a violation of rights” and thus likening the practice to other atrocities such as genocide and torture, which seemed to surpass the boundaries of tolerance (Hellsten 2004: 249; also see Konner 1990).

Much like the rhetoric of fistula, Alice Walker, an author and activist who wrote about FGM in the 1990s, concomitantly indicted “African culture,” Islam, and African men, for enslaving women’s bodies. In *Warrior Marks* (1993),²⁴ a book detailing her process of filming a documentary on “female genital mutilation” and the “sexual blinding of women,” Walker’s musings about her own romantic relationship leads her to reflect upon her assumed impossibility of such unions in Senegal:

²⁴ And later in Walker’s novel *Possessing the Secret of Joy* (1992), where the main character Tashi’s dysfunctional sex life, painful childbirth, deformed child, malignant marriage, and profound unhappiness are all attributed to female genital cutting.

My beloved called to wish me Happy Valentine's Day, and it feels odd to think of a Valentine's Day kind of love here, where men have three and four wives, all of them poor, and even the mosque is forbidden to women until after menopause, when they are considered closer to being male. We strolled past the mosque one day, and it looked totally dead and boring... What has happened to these people, that they seem so joyless and oppressed? Is it Islam, as some suggest, which encourages passivity and desertification? Everything, including massive overgrazing of livestock, turning the fertile land into desert, is merely "the will of Allah"? I think genital mutilation plays a role. The early submission by force that is the hallmark of mutilation. The feeling of being overpowered and thoroughly dominated by those you are duty bound to respect. The result is women with downcast eyes and stiff backs and necks (they are of course beaten by fathers and brothers and husbands). And men who look at a woman's body as if it is a meal. (Walker and Parmar 1993: 69)

Like in the semiotics of fistula, Alice Walker sees "African men" as an uncomplicated whole—dominating and beastly, molding female bodies into submission by force and "African culture and traditions" as harmful, coercive, and static. Indeed, Walker frequently discusses men's role within their "mutilating culture," calling African men "backward" and "slave-masters" (among various other insults) (Walker and Parmar 1993: 36, 43). In a poem, Walker writes:

Everything and/ everyone/ to the girl child/ of Africa/ appears to be/ against her/.../As I always suspected/ She/ the very foundation/ of life/ and all that is/ lovely/ is deliberately/ spoiled/ ruined/ abused/ tamed/ made into an evil/ scowling/ woman/ who encounters/ the world/ with split mind/ and filed teeth/.../The African mothers/ forced to "forget"/ their pain./ The African fathers/ trapped/ at last/ into a shamed/ and frustrated/ secret/ brotherhood/ the bond/ being / their/ daughters'/ mutilated flesh./ (Walker and Parmar 1993: 55-59)

"Africans are doing OK, basically," Walker concludes, "if they'd just stop hurting themselves" (Walker and Parmar 1993: 50). Just as fistula has become two decades later, female genital mutilation was (and, to some extent, still is) seen as the embodied manifestation of a diseased culture, inflicting its wounds on the "female child of Africa," who in her "vulnerable loveliness" is rendered helpless and voiceless and thus direly requires the intervention of Westerners (Walker and Parmar 1993).

Largely due to the work of scholars such as Obermeyer (1999), Gruenbaum (2001), and Abu-Lughod (2002), among others, the anthropological community's stance on the issue shifted in the 2000s, putting the practice in the context of people's lived experience and recognizing women's agency in their choice to undergo such operations. However, among NGOs and human rights groups, the language surrounding female genital cutting and fistula remains so similar that many who claim a vague familiarity with fistula often erroneously cite it as a result of "FGM." Despite the wide recognition among scholars and clinicians that most female genital cutting has little causal connection to fistula (Browning, Allsworth and Wall 2010),²⁵ many NGOs continue to advertise the link. Dimol, one of the first NGOs working with fistula in Niger, ran a wide-reaching radio campaign across Niger in 2004 that publicized "FGM" as a *direct cause* of obstetric fistula (Dimol 2004: 4).

Using similar rhetoric as espoused in anti-female genital cutting campaigns, since 2000, a moral crusade against sex trafficking has developed. According to an examination of the literature, in 1970-1980 only one scholarly article mentioned the term sex trafficking. This corpus of literature grew to 18 in 1980 to 1990, 183 the following decade, and 4,356 between the year 2000 and 2009. In the four years between 2010-2014 alone, 8,470 articles focus on sex trafficking. Sex trafficking, sometimes known as "sexual slavery," has captured Western attention with tales of prepubescent girls stolen from their homes (or sometimes sold off by their family) and bought by venal criminals who exploit and capitalize upon girls' virginity, purity, and youth. In a typical presentation of the "crisis," the NGO the Population Media Center explains:

The UN estimates that approximately 1 million girls are forced into the commercial sex industry each year...These girls are sold by their families for money, tricked into going

²⁵ "Type I and Type II female genital cutting are not independent causative factors in the development of obstetric fistulas from obstructed labor" (Browning, Allsworth, Wall 2010).

with the promise of a job or marriage, or kidnapped and forcefully taken away. They are taken to brothels where they are raped and abused into submission and then forced to have sex with as many as 30 men each day, usually without any type of protection... Beyond the physical consequences, these girls suffer immense psychological harm. Even if they are able to escape, girls are often not accepted back into their communities and are forced to live a life of poverty, disease, shame and isolation. (Population Media Center, n.d.)

Sex trafficking has ignited a moral crusade in the West whereby the worst forms of cruelty and iniquity are portrayed as the norm, collapsing the distinction between coercive trafficking and voluntary migration (with a particular distance from publicly detested—but far more prevalent—economic migration). In her book *Sex at the Margins* (2007), Laura María Agustín critiques this sensationalist coverage of sex work (termed, she argues, without much discretion or meaningful distinction as “sex trafficking”): “The focus is on the age of a victim, her helplessness, and the barbaric conditions she is forced to endure. Repeated continually with little variation, these treatments keep the gaze squarely on the non-European Others who have moved onto the sex scene. Statistics are tossed out without sources and the focus stays on miserable tales of a few individuals” (3-4). Agustín also notes the conflation between migrant, sex worker, and sex “slave” in the concept of sex trafficking:

The label migrant goes to poorer people who are conceived as workers with no other desires or projects, but when migrants are women who sell sex, they lose worker status and become “victims of trafficking.” The obsessive gaze on poverty and forced sex disqualifies working people’s participation in global flows, flexible labour, diaspora and transnationalism. (Agustín 2007: 191)

As is standard of other moral crusades, just as the victims are poor, oppressed, and without choice, the perpetrators are painted in a single shade of malevolence. As Ronald Weitzer states, “Customers are labeled ‘sexual predators’ that brutalize women, and traffickers are vilified as predators, rapists, and kidnappers involved in organized crime and sexual slavery” (2007: 452). The director of the UNESCO Trafficking Project, David Feingold (2010) argues

that the discourse surrounding sex trafficking reflects a “flight from complexity,” driven by an “overwhelming craving for a simple narrative of innocence debauched, a wrong that can be righted by the apprehension of an evildoer” (61). Villains become caricatures of pure evil, while the victims are diluted into one-dimensional, voiceless girls, defined by their meekness and lack of agency or autonomy. The misconceptions born from such sensationalist understandings of migrants who participate in sex work results in a veritable “Rescue Industry” formed to save its perceived victims (who often do not need saving). More than being impotent and unnecessary Agustín argues that, “those declaring themselves to be helpers actively reproduce the marginalization they condemn,” while transforming themselves into “disturbingly important figures” (2007: 5, 8).

Sex trafficking is then applied to vastly different circumstances surrounding prostitution, the only criteria the relocation of an individual to sell sex. The sex trafficking metanarrative overlooks the diversity in sex worker’s experiences. As Weitzer states, “There are *multiple migration trajectories and worker experiences*, ranging from highly coercive and exploitative to informed consent and intentionality on the part of the migrant. Yet, the crusade presents only the worst cases and universalizes them” (Weitzer 2007: 454). Similarly, Feingold (2010) notes that sex trafficking isn’t a discrete act, rather it is a process that defies simple categorizations, most often representing “a migration event gone awry” (Feingold 2010: 69).

As Doezema states: “The effect of these motifs of deception, youth/virginity, and violence is to render the victim unquestionably ‘innocent.’ Desperately poor, deceived or abducted, drugged or beaten into compliance, with a blameless sexual past, she could not have ‘chosen’ to be a prostitute” (1999: 36). Because the widely-consumed narrative of the sex trafficking victim requires her innocence, purity, and total victimization, a woman who consents

(and perhaps eagerly seeks out) opportunities to migrate across borders (sometimes knowing of future sex work) is erased in the narrative and the numbers, even if she is subsequently exploited. Seen as too complicit in her victimization, her suffering is not sufficiently compelling for a global audience. Much like the dramatic narratives surrounding fistula, sex trafficking narratives have capitalized on “one of the most powerful symbols in the pantheon of Western imagery, the innocent, young girl dragged off against her will...to satisfy the insatiable sexual cravings of wanton men” (McDonald 2004: 158). Then, largely due to misconceptions surrounding the phenomenon of sex trafficking, its solutions are misguided, encouraging governments to control migration rather than controlling coercion, exploitation, and deception. According to Feingold (2010), “Adult women are infantilized, protected from trafficking by depriving them of the right to unsupervised movement” (71).

The presentation of women of the Global South as helpless or childlike reflects what Chandra Mohanty identifies as the “colonial gaze” of Western onlookers: “Third world women as a group or category are automatically and necessarily defined as: religious (read ‘not progressive’), family oriented (read ‘traditional’), legal minors (read ‘they-are-still-not-conscious-of-their-rights’), illiterate (read ‘ignorant’), domestic (read ‘backward’)” (1998: 22). The tropes of cultural deterioration, dangerous masculinity, and girl-child victimization typify discourse surrounding female genital cutting, sex trafficking, and (most recently) fistula, illustrating the extent to which myths of cultural primitivism have gained a wider global currency. All three of these perceived crises place the sexuality of both men and women of the Global South under critical public scrutiny, producing a stark binary opposition of good versus evil—female innocence, purity, and passivity contrasted with male potency, brutality, and moral corruption. Indeed, Western interest in fistula may represent the newest repackaging of colonial

messages about the “dark continent” as a place stripped bare of morality whose barbarism victimizes its most vulnerable and innocent: girl children. This sentiment is reflected in a *New York Times* article on fistula, which poignantly concludes with the words of Dutch fistula surgeon Dr. Kees Waaldijk: “To be a woman in Africa ... is truly a terrible thing” (LaFraniere 2005).

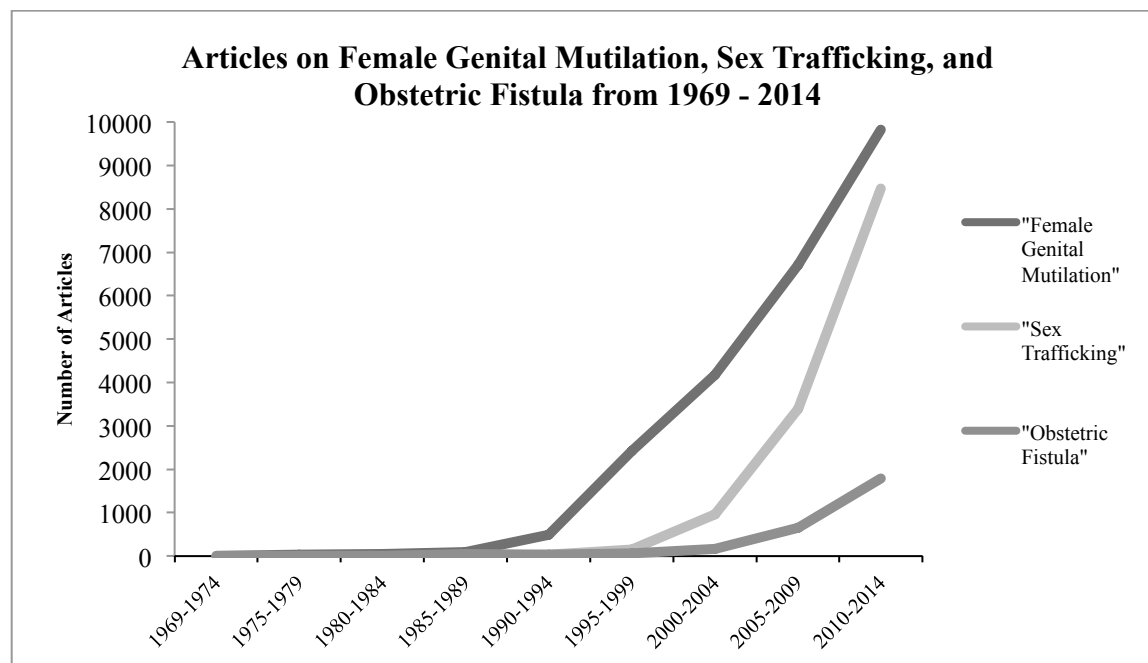


Figure 4.1: Articles written on female genital mutilation, sex trafficking, and obstetric fistula from 1969-2014 (found using Google Scholar). “Female genital mutilation” became a popular topic of discussion circa 1990, sex trafficking around 2000, and obstetric fistula around 2005. Each of these topics can be viewed as successive moral panics, where journalistic and popular interest grew rapidly.

4.2 The Fistula Narrative

Fistula is above all else a consequence of certain ancestral practices which people find difficult to rid themselves of: early marriage, first time births at parents’ homes which are often far from health centers, and the stubbornness of the grandmother in playing the role of sex educator.

— Harouna et al., *La Fistule Vesico-Vaginale de Cause Obstétricale*

As demonstrated by the above quotation from a peer-reviewed tropical medicine journal, at various points throughout the fistula narrative, “culture” (or sometimes religion) is indicted. Culture first intervenes when the woman is a mere child, encouraging her premature sale into

conjugal life; then during her labor, when often it is patriarchal cruelty or cultural norms encouraging birthing at home or alone that keep the woman from appropriate medical care; and finally after the development of her fistula, when cultural understandings of corporeal purity and reproductive success result in her degeneration into a social non-entity. These cultural failings are then juxtaposed with the potency and efficacy of fistula reparative surgery, seen to mend the physical and social self all in one technical performance. Together, these elements have congealed into an eminently recognizable fistula brand. In the remainder of this chapter, I explore the three primary tropes—or plot devices—that constitute this brand: the archetypical sufferer, archetypical forms of suffering, and the myth of surgical potency.

Plot Device #1: The Archetypical Sufferer and the Child Bride

Poor obstetric care was not the only reason for the fistulas. The other big problem was, and still is, that of child marriage...Girls may be betrothed at the age of eight and can be married as young as twelve...They are not mature enough, emotionally or physically, to cope with a sexual relationship. It is rape, really—condoned by their parents.

—Catherine Hamlin, *The Hospital by the River*

The first, and most basic, element to the fistula narrative is the portrait of the woman with fistula herself. The fistula narrative brings to the forefront a singular helpless sufferer: she is young, virginal, and without culpability. She is a victim in all senses of the word—she is acted upon, she does not act. Harm is done to her, never by her. She is a passive receiver of injurious decisions made by her (male) kin or husband regarding her life and her body. She is the Madonna, representing an almost religious purity. The power of this narrative comes in its moral clarity. In stripping her of her agency in the development of her fistula, she is also stripped of agency in its remedy. She is no longer the protagonist of her own narrative. Instead, organizations, clinicians, and, ultimately, donors—not she—are framed as the actors of her redemption story. Just as bad is done to her, so is good through the “gift” of cure.

In her examination of the media's coverage of famines in Africa, historian Susan Moeller (2002) critically examines the media's use of children. "Starving children are the famine icon," she explains, "Skeletal children personify innocence abused. They bring moral clarity to the complex story of a famine. Their images cut through the social, economic, and political context to create an imperative statement" (Moeller 2002: 36). This focus on children makes geographically (and culturally) remote, complicated, and morally ambiguous disasters comprehensible to a lay Western audience. She argues that even if the focus on children "is a false or distorted consciousness, a simulacrum of the event," through the pleading eyes of children, audiences in the Global North will be shaken from their "compassion fatigue," urged to take action (37). The media recognizes and fuels this fetishization of children. In an interview Moeller conducted with Marc Charney, an international editor of the *New York Times*, Charney demonstrates the way in which narratives of suffering—and the victims they champion—are strategically constructed: "What I'm looking for, what's new in stories on international affairs, are those on women and children—like the piece we did on rape as a weapon of war or the one on child soldiers" (quoted in Moeller 2002: 43-44).

Children are focused on not only because their youth allows them to be seen as cultureless—not yet linked to Western stereotypes attached to their parents' culture, color, or political environment, they also come in first on what Moeller calls the "hierarchy of the innocent," or the "operative ordering of who in the world is considered to be most deserving of protection" (2002: 48). Of all sufferers, children most effortlessly meet the tacitly understood Western requirement that victims be one hundred percent innocent non-participant, followed closely in the pecking order of compassion by pregnant women, teenage girls, elderly women, all other women, teenage boys, and lastly, all other men (Moeller 2002). It is unsurprising that

crises that receive the most attention in the West are those that disproportionately affect children and their young mothers. Fistula is then perfectly situated for successful media exposure, implicating at once the top rungs of the “hierarchy of the innocent” embodied by one perfect victim: young, pregnant girls who inevitably suffer the loss of their infants.

Not only does the girl with fistula play into a Western notions of and preoccupation with the innocence of children (Manzo 2008; Wark 1995) and the moral panic surrounding their sexuality (and thus the need to protect them from predators), but it also allows for the treatment of sexuality without conceptualizing girls as sexual subjects themselves. Because much Western (particularly U.S.) attention over the past several decades has focused on the loss of children’s proper sexual boundaries, emanating from the failure of children to validate adult fantasies of childhood innocence, the public gaze has turned an accusatory eye towards the sexual predation of young children (Lancaster 2011; Weitzer 2007).

The fistula narrative’s focus on “early” marriage permits for sexual engagement while still preserving a young woman’s moral (if not physical) chastity in a way that highlighting women on the other end of the spectrum of risk—a mature woman who develops fistula after several intended pregnancies—would not. Young girls with fistula are thus seen as victims, wronged by African men (indeed, it is not unusual for presentations of fistula to open with a pubescent—or pre-pubescent—girl’s sale into conjugal life by her father and subsequent “rape” by her new husband).

Fistula sufferers are largely portrayed as mere children, referred to as “girls” rather than women, and are thereby systematically stripped of the agency that is assumed of adulthood (see, for example, Hamlin 2001; Kristof 2005). As the narrative goes, vulnerable to the predation of men, young girls are wed to men they often do not know and carried off against their will at an

early age, becoming pregnant as soon as they are biologically able and leading to a horrific labor which culminates in the development of fistula. Because fistula is caused by obstructed labor, the fistula narrative often presents “early” marriage as the main causal factor—resulting in pregnancies among girls whose pelvises are too small and “immature” to birth a fully developed child (Wall 1998). Fistula is then framed as the physical evidence of corrupted cultural practices, invoking images of despoiled youth and tainted innocence—of children who are no longer allowed to be children, as they are drafted into marriage and its attendant onerous duties.

The narrative’s focus on first pregnancies means that the young girl is left without living children. Unable to achieve the cultural expectation of bearing children, she is left alone and without local value in cultures commonly deemed patriarchal and pronatalist.²⁶ One *New York Times* journalist, for instance, describes the fistula documentary *A Walk to Beautiful* as, “a complex and quietly devastating indictment of chauvinist societies that see women as lovers, mothers and servants, and treat anyone who can’t fulfill those roles as a nonperson” (Zoller Seitz 2008). As the story goes, a young girl is sold off when she is still a child and forced to bear an older man’s children before she is emotionally or physically mature. During labor she is too small (and often too malnourished) to birth normally, and the child dies. What follows in the narrative is frequently a discussion of her social isolation and potential future infertility, which ultimately exacerbate her loss of social utility and her descent into a non-entity. Unable to bear live children, she is seen as broken, valueless, and thus is cast aside.

Plot Device #2: Archetypical Suffering and the Social Pariah

Because they are so offensive to be near, fistula sufferers are invariably divorced by their husbands and banished from their village. Theirs are lives of loneliness and despair, often in some ruined dwelling away from everyone else, or they may be forced to beg for a living in the town.

²⁶ It is estimated that of the pregnancies which cause fistula, 90-98% of the births are stillborn.

—John Little, *Catherine's Gift*

“These are the women most to be pitied in the world,” said Dr. Hamlin. “They're alone in the world, ashamed of their injuries. For lepers, or AIDS victims, there are organizations that help. But nobody knows about these women or helps them.”

—Nicholas Kristof, *The New York Times*

The gendered cult of innocence gains additional traction when integrated into a formula of archetypical suffering, culminating in the figure of the social pariah. Following the onset of their incontinence, women with fistula are said to be mistreated, shunned, and isolated by their kin and community, divorced from their husbands, and put up in ramshackle huts by themselves somewhere outside the community. There, they are left to vegetate in their own suffering (wild animals are often imagined to circle these huts, preying on the crippled bodies of small and helpless women). Apart from the occasional rotten leftovers thrown to them, the women are left to their own devices, driven to, in their isolation and abandonment, the depths of depression, and even suicide.

Examples of this tightly scripted narrative can be found across the wide range of global media, including several award-winning fistula documentaries (Salgo 2010; M. Smith 2007), the well-publicized biographies of the co-founder of the first fistula hospital in Ethiopia (Hamlin 2001; Little 2010), and the world's newspapers and media outlets (O'Kane 1998; Warner 2014). In the course of this coverage, women suffering from fistula have been likened to “septic tanks” (West Africa Fistula Foundation 2011), along with having attained the dubious fame of being called “the most wretched people on this planet” (Kristof 2009). Academic peer-reviewed articles on fistula emanating from the fields of public health and medicine engage this same vocabulary of suffering (see Castille et al. 2014; Harouna et al. 2001; Kabir et al. 2003, for some examples). Brugière (2012) stresses that, “In addition to the suffering caused by sterility, these women are often abandoned by their spouses. They are gradually ostracized, and left isolated, socially excluded and facing difficult economic deprivation. This affective and social isolation

leads to severe depressive state and even suicide.” Anoukoum et al. (2010) aver that obstetric fistula is an “eternal nightmare, making a woman a ghost, shut out from society” (72). Even Niger’s 2012 Demographic and Health Survey states that on top of physical pain, fistula causes women “humiliation,” “tragic social consequences,” and a woman’s rejection by her family and husband (DHS 2012: 118).

Through the narrative of social stigmatization, abandonment, and isolation, fistula is intentionally linked to other illnesses that carry symbolic power. It is not a coincidence that women with fistula have been coined “the 21st century’s lepers” (Kristof 2005, 2009, 2012). Links with leprosy evoke powerful images of grotesque bodies, social stigma, and, most importantly, spatial separation. This trope of segregation and seclusion, so evident in historical treatments of leprosy, permeates accounts of fistula (“Often she is repudiated by her husband, rejected by her village, and doomed to try to survive on her own” [Castille et al. 2014: 77]). In discussing punitive notions of disease in relation to cancer, Susan Sontag writes that, “Leprosy in its heyday aroused a similarly disproportionate sense of horror. In the Middle Ages, the leper was a social text in which corruption was made visible; an exemplum, an emblem of decay” (1990: 58). Through the link between leprosy and fistula, the Western imagination is seeded and fistula takes on the symbolic power that leprosy once had, both in terms of the alleged “pollution” of the afflicted and their expulsion from the community. The trope of banishment is particularly poignant here. It calls forth images of those who have historically been exiled from the city: witches, criminals, dissidents, and the variously infected.

Plot Device #3: Surgery and Technocratic Solutions

While the effects of fistulas are traumatic, the condition is surprisingly easily to treat and has a 90% healing rate. One operation costs US \$300.

—The Federation of American Women’s Clubs Overseas

A simple reconstructive surgical procedure can repair over 90% of fistulas. While the surgery is straightforward, few surgeons specialize in fistula repair in the countries with the most cases... The average cost of fistula repair, including the surgery, post-operative care, and rehabilitation support, is around \$300. This is far beyond the means of most women currently living with fistula.
—EveryMotherCounts.org

In the logical redemption that follows the loss and isolation faced by fistula sufferers, the hospital with its biomedical technologies emerges as a place of both physical healing and social rebirth. There, an ailing woman is relieved of her incontinence through a surgical intervention. In popular (and even some academic) literature, fistula tends to be portrayed as a quick and easy “fix”—a technocratic solution akin to vaccinating children or handing out mosquito nets. The reported success rates for fistula surgery vary, but typically range between 85% and 95% (Jatoi et al. 2008; Mselle et al. 2011; Ndiaye 2009), and may be as high as 98% (Nafiou et al. 2006) (which will be discussed in the following chapter). In part, the ostensible ease but enormity of impact in a case like fistula—a \$300 surgery that takes no more than two hours, and often as little as twenty minutes (IRIN 2009; Kristof 2005)—has made fundraising for this injury so palatable for donors.

On the website www.samahope.org, potential donors can fund part or all of “a life-changing surgery” for a particular woman of their choosing by browsing through patient photographs and profiles.²⁷ Thereafter, donors receive regular “progress” updates on “their” patient. This discourse supports the notion that fistula, as an acute crisis, “can be redressed with greater, faster impact” than chronic diseases that require more longer-term, costlier solutions (Manderson and Smith-Morris 2010: 10). The focus on straightforward fixes is a strategic final element to the fistula narrative, particularly appealing to possible donors and donor agencies. The promise that an hour (and a paltry sum of money to most middle-class Westerners) could

²⁷ A similar strategy, whereby potential funders can browse through pictures and profiles of brown-skinned sufferers, has been adopted in various humanitarian charity campaigns. See for example Erica Bornstein (2010), “The Value of Orphans.”

pull an innocent girl, mistreated by her kin and culture, from the depths of suffering and social isolation renders non-action from the Western public morally deplorable.

4.3 The Worthy Victim, the Villain, and the Western Protector

The Global North's interaction with crises in the Global South demonstrates that compassion is not blind and victimhood is a status that must be earned. It is also earned not only through suffering, or unjust persecution, but through an array of qualities that position the sufferer as pure, innocent, nonthreatening, and worthy of intervention. Since European colonial times, groups and individuals have been divided into discrete categories: those deserving of access to development and humanitarian assistance, and those who are not—worthy versus unworthy. The worthy victim, or as Malkki (1996) calls her, the “exemplary victim,” are imagined as helpless, in need of aid, and void of particulars.

In *Manufactured Consent*, Herman and Chomsky (1988) forward a “propaganda model” in which the media's presentation of news, suffering, and victimization are biased by political structures and geopolitics. They explore the ways in which “worthy victims” and “unworthy victims” are formed, positing that victims of the U.S.'s “enemy states” are subject to more intense and indignant coverage than victims of the U.S. or U.S. client states. By focusing on ‘worthy’ victims, the perceived iniquity of enemy states is reinforced and U.S. intervention and hostility is further justified. For example, they assert that the powerful and emotionally laden word ‘genocide’ is applied readily to cases of victimization in enemy states, but rarely (if ever) to cases of victimization by the U.S. or its allies. For example, the Hussein regime of Iraq committed genocide against its people, but the U.S. ally Turkey merely “repressed” its Kurdish population.

Using media coverage as a proxy for victim “worthiness,” Herman and Chomsky compare the mass media coverage of the murders of a Polish priest in 1984 to the coverage of the murders of dozens of priests during the same period in U.S. “client states” of Latin America. News of the slain Polish priest dominated headlines and both quantitatively and qualitatively dwarfed coverage of the others murders, which went barely noticed in the public. If media coverage can be used as a proxy for public value, they claim that the Polish priest was valued between 137 and 179 times that of any single priest victimized in a US “client state.”

Since the late 1980s, not much has changed. Only some victims are privileged, only some forms of suffering recognized. Denizens of the Global North are often blind to the ways in which they, as citizens of powerful, moneyed, and largely Christian countries, privilege certain forms of suffering while ignoring others, tacitly deeming some sufferers “unworthy.” It is not a coincidence that those most capable of arousing Western sympathies, that those whose anguished (but often beautiful) faces populate the covers of websites, TV ads, or NGO publications, are fairly homogenous. They are young, female, and brown. They are the quintessentially non-threatening.

“Mothers and children make ideal victims,” writes Moeller (1999: 107) in her discussion of the television coverage of famine. “Men associated with violent political factions can starve by the thousands without creating a flutter of interest in their victim status. The men are culpable, it is assumed, in not only their own deaths, but in the deaths of the truly blameless. Only when victims have been identified as ‘bona fide’ are they candidates for compassion,” she asserts. In a study on the reactions of Scandinavians to news coverage of atrocities around the world, Höijer (2004) found that while coverage of children, women, and the elderly in Macedonia elicited compassion and indignation, the televised suffering of middle-aged men did

not. A man in a refugee camp looked into the camera, begging to be brought to Norway, begging to for help. Instead of compassion, he aroused sentiments of anger in research subjects. He was not considered sufficiently helpless, or innocent, rather, he was considered selfish and unmanly. One respondent said: “I thought it was a shame to behave as he did when you think about all the pregnant women and sick people. They need to be helped and he should have begged for them. He should have said: ‘Please help them!’”

In the “Politics of Virtue,” Deborah Mindry (2001) explains how poor, rural, women of color (sometimes referred to as “country women”) were idealized (and objectified) recipients of development and humanitarian intervention in post-apartheid South Africa. “Country women” were seen as more virtuous than men, more humble than urban women, and ultimately the most helpless, most impoverished, most oppressed, and most in need (and presumably deserving) of assistance. Development organizations operated within a “transnational politics of virtue” which constituted “women as benevolent providers” and “deserving recipients” of both development and empowerment (Mindry 2001: 1189). The countryside was envisioned as a “morally pure terrain” (ibid. 1207) where the politics of class, race, and power were rendered invisible behind humanitarian goodwill:

This story is about an imagined feminine “global family,” about the connections among women in far-flung places, in the “first” and “third” worlds. Implicit in the story are narratives of feminine virtue, of women who (simply because they are women) are concerned about others, of women who need to care for all the members of the “global family.” There is a politics of feminine virtue at work here that constitutes women in ways that are disturbingly similar to Victorian colonial discourses about the caring, selfless mother and that constitutes women along the familiar themes of domesticity and benevolence. (Mindry 2001: 1189)

Similar to Mindry’s case study, in the fistula narrative, young, poor, rural, dark-skinned girls are regularly positioned as the virtuous victims of their male kin, husbands, and community patriarchs. The fistula narrative is in line with pre-existing discourses of Africa(ns) where

Westerners are positioned as the agents of change and salvation for a continent full of laboring women, oppressed by African men. Indeed, twenty-five years ago Gayatri Chakravorty Spivak characterized British imperialism in India as “white men saving brown women from brown men” (Spivak 1993: 93). Spivak critiqued this approach, saying that brown women were “doubly marginalized” both by patriarchy and Western imperialism that silenced women’s voices and overlaid a moral discourse on their experiences. Most articles discussing obstetric fistula vary little from the deeply rooted semiotics of intervention in the Global South (and particularly in sub-Saharan Africa) whereby white surgeons save African girls (and women) from African men who sell girls’ bodies into premature marital unions, inhibit them from receiving timely medical care in the face of obstetric emergencies, and reject their broken bodies when they fail to produce healthy babies.

The erasure / villainization of African men can be traced back to colonization and European imperialism. However, even more recently, movements in international development have unconsciously perpetuated this paradigm. Emerging in the 1970s, the practice of focusing on women in development is based on the assumption that if African men were given money, they would be much less likely to reinvest it in their families than their wives would be, instead buying drinks for their friends, going out, or investing in shows of wealth or status. Conversely, the assumption is that women are more adept at saving and investing wisely, and more likely to channel resources to their children’s and family’s health and education. In an unsurprising repackaging of stereotypes of both sexes, men are expected to spend money only on themselves while women are expected to labor for everyone else. As a result of such assumptions, women (and girls) have become the flag-bearers of international development work, their faces

disproportionately populate fundraising materials and beneficiary rosters, and nearly every intervention integrates “gender,” focusing heavily on improving women’s access to resources.

Conversely, African men have become caricatures in the Western imagination, fall-men for everything that befalls African women and children. The inclusion of women in the development agenda was in response to the historic erasure of women of the Global South. However, the pendulum has swung to the other extreme. In discourse, news, and media consumed by Westerners, too often African men are now either absent, or present only as they hold guns, rape women, reject their wives, participate in extortion and corruption, or join the growing ranks of religiously motivated extremists.

In a recent TED talk entitled “Don’t Misrepresent Africa,” Leslie Dodson discusses how the development industry pivots around the image of the Madonna and child (Dodson 2011). There is no room for men, she argues. Indeed, in Western engagement with sub-Saharan Africa, there is a strict gender divide: suffering and victimhood belong to women while perpetration and barbarity belong to men. Western anger and indignation is channeled to African men, while Western compassion to women and girls.

Girl’s education, girl’s business skills, women’s health, women’s hygiene—there are real consequences of forgetting men and boys. While the “focus on women” aims to empower women, it may in fact strip women of agency and reify notions of gender, buttressing claims that naturalize women’s place in the home and as caretaker while reinforcing notions of men as deadbeat dads and cruel husbands. While the focus on only half the population serves fundraising purposes (as donor audiences infrequently respond to nuance—one is either a victim or a victimizer), these programs overlook that families, communities, marriages, and businesses do not operate in the absence of half their members. It is hard to critique development agendas

that aim to increase the power and status of women in places largely defined by patriarchal hierarchies. Still, by painting African women as the victims of African men, the real victimizers—which are blind to sex or gender—are overlooked: poverty and systemic inequalities.

Nigerian novelist Chimamanda Adichie (2009) criticizes the monolithic presentation of Africa common in the West, a “single story” of suffering and poverty, which, in its ubiquity, obfuscates complexity, nuance, and the diversity of experience. “Show a people as one thing, as only one thing, over and over again, and that’s what they become,” she warns. Adichie adds that these “single stories” are the result of power imbalances, “Stories . . . how they are told, who tells them, how many stories are told is really dependent on power. Power is the ability not only to tell the story of someone, but to make it the definitive story of that person . . . The single story creates stereotypes, and the problem with stereotypes is not that they are untrue, but they are incomplete. They make one story become the only story.” The branding of fistula—the prevailing meta-narrative of exclusion and separation, followed by the surgical “fix”—has subsumed all other experiences with this injury; fistula has been “single-storied.” In the ethnographic accounts woven throughout this dissertation, I introduce an array of competing stories that begin to unhinge the narrative framework that has thus far dominated fistula’s publicity.

4.4 Compassion Fatigue and the Race-to-the-Bottom

Milan Kundera wrote in *The Book of Laughter and Forgetting*, “The bloody massacre in Bangladesh quickly covered over the memory of the Russian invasion of Czechoslovakia, the assassination of Allende drowned out the groans of Bangladesh, the war in the Sinai Desert made people forget Allende, the Cambodian massacre made people forget Sinai and so on and so forth,

until ultimately everyone lets everything be forgotten” (1979: 9-10). Over thirty years later, this morbid chain of recognition, distraction, and forgetting has grown long.

There is no denying that the humanitarian marketplace is currently spiraling downwards in what I call a race-to-the-bottom of suffering. Media, humanitarian and development agencies, or those championing a particular cause, use ever more lurid language, vivid images, and resolute claims to the superlative states of suffering, exposition of “worthy” victimhood, in an attempt to pierce the callouses formed from unrelenting exposure to seemingly endless human crises rendering the public anesthetized to commonplace suffering.

Funding for humanitarian aid occurs in what Clifford Bob (2005) calls a “Darwinian arena”—a marketplace of suffering which functions shockingly similarly to the business world, resulting in ‘better’ victims (more tragedy for your money) and increasingly cheaper solutions. Although the fundraising strategies adopted by humanitarian organizations are ultimately detrimental to their cause (and of course to the people for whom they advocate), these strategies do help organizations meet their short-term funding goals.

Although girls continue to undergo genital cuttings before they are of the age to consent, and although young women continue to be trafficked into sex work, lured by false promises of honest work or perhaps sold by their families who could not (or would not) conceive of another option for their daughters, the coverage of these “crises” has abated. The public’s interest has waned—perhaps another example of “compassion fatigue,” or perhaps editors weary of dips in readership, or nonprofits that feared decreased donations acted first, finding a new crisis, finding fresh meat. And although fistula is the *cause célèbre du jour*, it will not continue to be so. Perhaps next month, or perhaps next year, fistula too will fade from the Western popular consciousness, only to be replaced by the next crisis—supplanted by the new brown-bodied girls

who need saving.²⁸ Perhaps tomorrow it will be the crisis of rape in India (every mention of “rape in India” in the *New York Times* since 1970 has happened since 2010, for example).

But despite rallying calls to eradicate fistula in a generation, many of today’s young girls in the Global South will reach maturity in places with inadequate access to maternal health care, and will suffer the consequences of poverty and inequality. But, Western attention will be elsewhere, moved on to the next crisis which too holds empty potentials of quick solutions.

In the world of Western aid and non-profit fundraising (where innumerable causes co-exist and compete, where human suffering is displayed in various forms and manifestations, where looming in the corner of nearly every website is a bolded “donate” icon), organizations are often compelled to fight tooth and nail for a limited pot of money, which has led to a new “race-to-the-bottom” of suffering. Humanitarian organizations championing fistula (and numerous other conditions, including cleft palate, HIV, or malnutrition) have begun to engage in a battle of the superlative pitiable, all making one claim: our victims are the most deserving; our victims suffer the most. Such assertions are frequently followed by the promise of total redemption, of a quick and efficacious solution: a single pill, a simple surgery, a cheap bed net. However, these kinds of appeals have not been without consequences.

In the following two chapters of Part I, I explore how the fistula narrative is maintained despite contradicting evidence, examining how frequent modest surgical success outcomes are translated into jubilant expressions of biomedical potency that compliment the fistula narrative’s final plot device of physical transformation. In chapter six, I examine the consequences of the fistula narrative, both on the prioritization and implementation of fistula programming, and on ways the Global North thinks about and interacts with the Global South.

²⁸ Recent news stories suggest that perhaps an epidemic of rapes in India (and beyond) will summon Western attention.

Chapter 5

The Social Life of Data

In the popular book *Damned Lies and Statistics*, Joel Best (2001) warns that while numbers are frequently understood as “hard facts,” statistics are social artifacts, often constructed by invested parties and used as weapons, deployed strategically to influence public opinion and policy on social issues. Numbers are forwarded (and sometimes fabricated) by invested parties, disseminated by media, repeated and republished, consumed by the public, and ultimately reified as fact, despite their often-tenuous beginnings. Through manipulation and repetition, numbers take on a life of their own—they become indisputable.

In October 2013, I spoke with the director of the Danja Fistula Center. She and I discussed the widely circulated “ninety percent” surgical success rate that has been recited so extensively and pervasively that it appears to have lost its connection to evidence-based research, becoming a social fact unmoored in clinical practice. “Ninety percent,” she scoffed, shaking her head, “There is no way to live up to it. It is fooling the world in general.” She explained that the dissonance between expected and actual outcomes results in pressure on clinics to produce unreasonable, possibly untruthful, data:

When I interact with [a representative within Niger’s Ministry of Health], when I give our success rate of 30 or 40%, he’d look at me and say that it isn’t good. He’d say to me that, “We are looking for success rates above 60%.” They keep making us feel bad about it. They keep saying we aren’t doing well. Twice he has told me that he isn’t impressed, that I should be giving him better statistics, particularly since we are just a fistula hospital, but that the other centers have higher success rates. I calculated our success rate from February 2012 until July 2013. We had a 49% success rate in the two years combined. He said that it isn’t good.

Despite numerous clinical studies from Niger reporting often modest, but highly varied, success outcomes for reparative fistula surgeries, (placing the center’s 49% success outcomes

right in the middle of the spectrum of findings, which range from 24—89%, [see Table 4.1, Ascher-Walsh et al. 2010; Vanderputte 1985]), this diversity within the fistula narrative is effaced. Indeed, as discussed in chapter two, the influence of philanthrocapitalism on the humanitarian marketplace results in a donor and media fistula narrative that emphasizes the relative ease and inexpense with which fistula can be addressed through surgical intervention. Fistula surgery is also portrayed as highly efficacious, frequently reported to successfully “cure” women in the overwhelming majority of cases, most commonly cited as a general 90% success rate (Clinton Foundation 2014; Engender Health 2014; Fistula Foundation 2014; Wikipedia 2014; Women Deliver 2013, among others).²⁹

Rather than “hard facts,” statistics are better thought of as an end result of a long series of choices of what to count and how to count it, often mediated by the interests of those who do the counting. I argue that the widely cited 90% success rate of fistula surgery may not reflect actual surgical outcomes, but rather the end point in a carefully constructed narrative. Yet, the 90% success rate diminishes the credibility (and ability to compete for funding) of organizations that claim significantly lower success rates, thus exerting pressure on organizations and fistula centers to systematically overcount success (defined here as continence) and undercount failure (defined, in turn, as the inability to restore continence).

When fistula surgery is performed under ideal conditions, on ideal patients (women who are “new cases” with what has been called “simple fistula” [de Bernis 2007]), surgical intervention *can* be quite effective. However, among my research sample of women with a wide

²⁹ High surgical success rates are not confined to donor and media narratives, as they permeate even some academic literature—particularly general overview articles about fistula and articles about specific aspects of fistula that foreground success rates as general introductory information (see Miller et al. 2005). For example, in an epidemiology dissertation on fistula prognosis, Veronica Frajzyngier (2011) introduces fistula, claiming that, “The majority (80-95%) of fistulas can be closed surgically” (6). In a review piece on obstetric fistula, Semere and Nour (2008) write that, “About 80% to 90% of women with VVF can potentially be cured by simple vaginal surgery” (196). Such claims are common.

range of fistula types and previous surgical history, surgical intervention was both more difficult for women to access and less successful than commonly depicted. Of the 61 women who underwent surgery during the clinical stay at which they were interviewed (out of a sample of 100 women, 86 of whom were actively seeking surgeries), only 22 women (36%) attained continence, while 39 women (64%) remained incontinent.

In this chapter, I reconcile my data with the fistula narrative's expected surgical outcomes. I present the surgical success findings from my own sample and compare these findings to those of other studies in Niger and elsewhere. I outline some of the obstacles to measuring and comparing fistula surgical outcomes across studies, including the lack of standardization of categories or in the definition of surgical success. I examine how the ways in which "success" is defined and measured may result in success rate inflation, and thus partially account for large discrepancies between surgical outcomes. Finally, I argue that the international humanitarian marketplace shapes how data are produced and how data are deployed, whereby surgical success rates are translated from clinicians and researchers for public consumption.

5.1 Surgical Outcomes for Research Sample: Considering Modest Rates of Success

I found that of the women in my research sample who were finally able to secure surgeries after months (or sometimes years) of waiting, their surgeries frequently failed. Of the 61 women who underwent surgery during the clinical stay at which they were interviewed (out of a sample of 100 women, 86 of whom were actively seeking surgeries), only 22 women (36%) attained continence, while 39 women (64%) remained incontinent (see Table 5.1).

As an ethnographer, with some distance from women's clinical experience, I did not have access to all of the women's clinical diagnoses and thus cannot confidently report on closure

rates (which require a surgeon's diagnosis). Instead, my metric for "success" was directed by women's own self-evaluations, whereby continence was the sole criterion for "success."

Although there is a difference in the future prognosis of fistulas that cannot be closed and post-repair incontinence (which may be diagnosable and treatable through future surgical interventions), I have categorized all post-surgical incontinence together. For my purposes, I define surgical success as a binary: wet (incontinent) or dry (continent).

My definition of success followed the approach of Maulet, Keita, and Macq (2013) whereby "Continence was considered as the sole factor for repair success and recorded as a binary variable." However, with the understanding that some degree of incontinence may be normal following labors and aging, women were counted as "wet" only if their leakage was both persistent and subjectively reported as problematic.³⁰ Using this system of delimitation, five women who reported very occasional urine leakage but who still considered themselves "healed" (*warke*) were still categorized as dry/continent. Of note, five women in my sample who left their respective hospitals dry experienced repair breakdown within a few weeks of their return home—they are counted an incontinent.³¹

Of the 22 women who attained continence, 16 women (73%) were "new cases," having previously undergone zero or one surgery before the research period, while 6 women (27%) underwent two or more surgeries prior to the research period. Of the 39 women who did not

³⁰ I defined "incontinence" using the previous International Continence Society (ICS) definition as an "Involuntary loss of urine that is a social or hygienic problem" (whereas the current definition defines incontinence as the complaint of any involuntary loss of urine) (see Abrams et al. 2009). Additionally, I defined continence as the ability to hold urine without the use of any external apparatus or technology (such as through urethral plugs or through urinary diversion surgeries and colostomy bags, although no women in my sample had either of these).

³¹ Some of these women did return to their respective fistula clinics hoping to undergo an additional fistula surgery during my research period; however, others did not, and I was only able to follow-up with them by phone.

attain continence, 18 women (46%) were new cases, while 21 women (54%) were old cases.³² Confirming the findings of Holme et al. (2007), new cases were significantly more likely attain continence than old cases ($p=0.045$).

Outcome of Surgery by Repair Attempt of 61 Total Women					
		Continence		Incontinence	
		Number of women	Percent of sample	Number of women	Percent of sample
New cases	No previous surgeries	11		10	
	1 previous surgery	5		8	
	Between 0-1 previous surgeries	16	73%	18	46%
Old cases	2 or more previous surgeries	6	27%	21	54%
Total		22	36%	39	64%

Table 5.1: Surgical outcomes of 61 women who underwent fistula surgery during the research period. Data are divided by women who were continent and incontinent, and “new” versus “old” cases. Data collected by author. In total, 22 women were continent (36%) while 39 women were incontinent (64%).

Of the 39 women who did not undergo surgery during the research period, 9 were not looking for surgeries at the time of the interview (either because they came to the centers with other health complaints, came for cesarean section in a subsequent pregnancy, or because they were already healed but returned to the center for trainings, to collect money, or for various other reasons), 3 women were categorized as incurable (and thus not operated on), 2 women were treated with catheters, and 1 one woman died at the center of unknown causes before receiving surgery. The remaining 24 women did not receive surgeries during the research period due to long wait times, infrequent surgeries, and the preference of surgeons to operate first on more straightforward or simple cases. Nine of these women returned home without receiving

³² Due to the limitations of this study, my inability to ascertain thorough clinical information about each woman, and a lack of consensus regarding the classification of simple versus complex fistula, I was not able to delimitate “simple” cases from “complex” cases.

surgeries, while the remaining fifteen continued to wait at centers at the end of my research period. Of these 30 women who were seeking but did not receive surgical interventions, many had very large, complex, and potentially “incurable” or “inoperable” fistulas requiring operations that frequently surpassed the expertise and abilities of available surgeons.

Of the 39 women who did not undergo surgery during the research period, 31 had a surgical history (6 had never received surgery and 2 were cured by a catheter rather than surgical intervention). Of these 31 women, 10 (32%) were continent (dry) while 21 (68%) were not (wet).³³ When these 31 women who received surgery prior to (but not during) the research period are included in the total surgical success rate (along with the 61 who received surgery during the research period), the surgical success rate does not change significantly: 32 out of 92 women (35%) attained continence, while 60 women (65%) did not (see Table 5.2).

Outcome of Surgery by Repair Attempt of 92 Total Women					
		Continence		Incontinence	
		Number of women	Percent of sample	Number of women	Percent of sample
New cases	No previous surgeries	16		15	
	1 previous surgery	5		12	
	Between 0-1 previous surgeries	21	66%	27	45%
Old cases	2 or more previous surgeries	11	34%	33	55%
Total					
		32	35%	60	65%

Table 5.2: Surgical outcomes of 61 women who underwent fistula surgery during the research period and 31 who received operations before, but not during, the research period (but returned to fistula centers for other reasons). Data are divided by continent women and incontinent and “new” versus “old” cases. Data collected by author. In total, 32 women were continent (35%) while 60 women were incontinent (65%).

³³ This sample may be biased as women with unsuccessful previous surgeries were probably more likely to return to fistula centers than women who were previously cured (who had fewer reasons to return, but did return for trainings, to collect money, for C-Sections, or other health complaints).

Within my sample, by the end of the research period, women underwent a combined total of 278 previous operations (for an average of 2.8 previous operations each, or 3.0 surgeries each if the 8 women who did not receive any surgeries by the end of the research period are excluded). At the end of the research period, 44 women (44%) had undergone between three and eleven previously failed surgeries. Of the 32 women who were healed at the end of the research period (including ten women who were dry at the beginning of the research period), 16 (50%) were healed after their first surgery and the number of successful surgeries after the first continued to decline (5 [16%] were healed after their second surgery, 4 [13%] were healed after their third surgery, 5 [16%] were healed after their fourth surgery, 1 [3%] was healed after her fifth surgery, and 1 [3%] was healed after her seventh surgery). Although women received up to eleven surgeries, not a single woman was healed after the seventh surgery (see Figure 5.2).

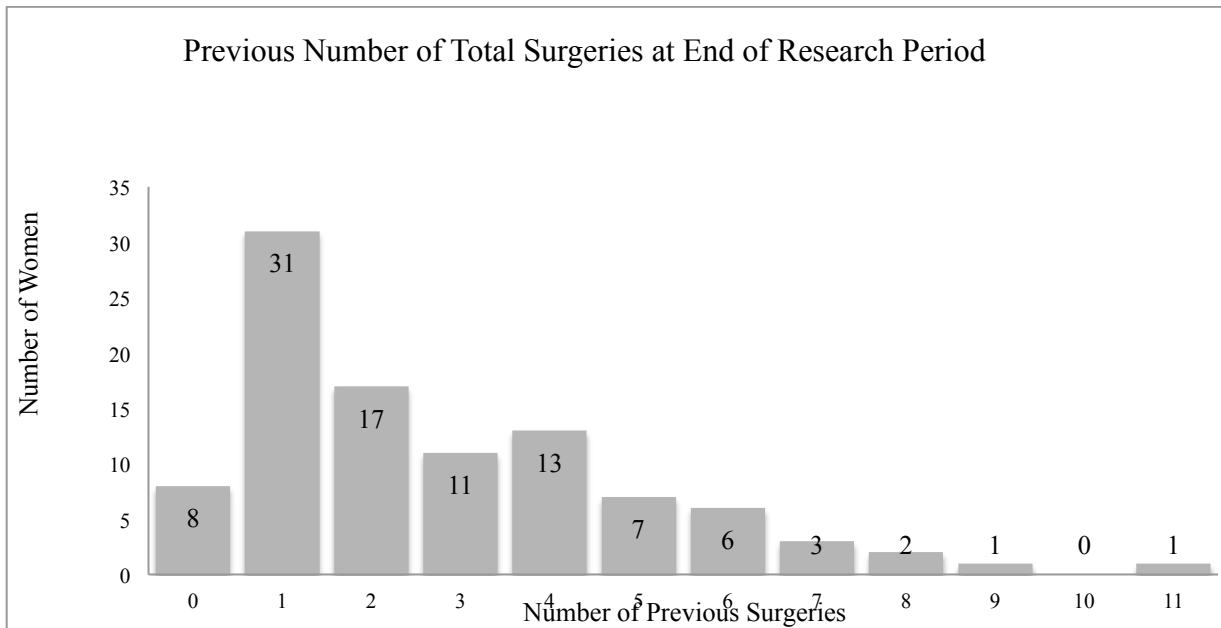


Figure 5.1: Number of previous surgeries among 100 women with fistula at the end of the research period. Women underwent between 0-11 surgeries. In total, women underwent 278 operations, with an average of 2.8 ± 2.2 operations each.

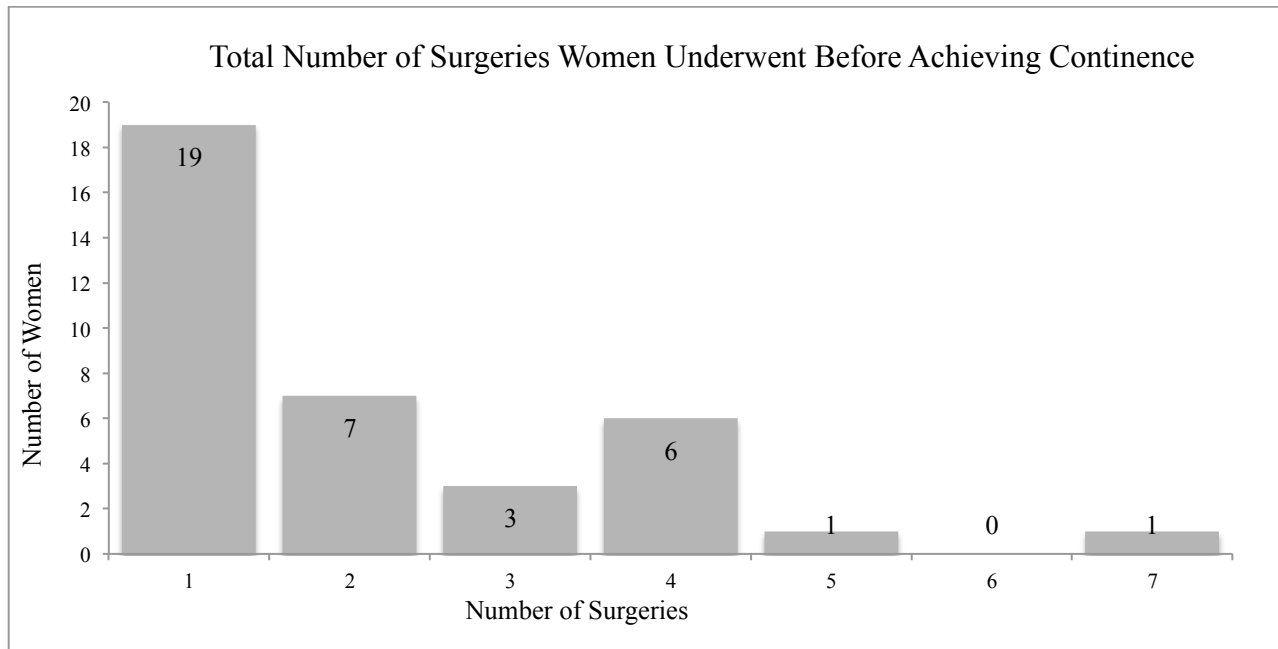


Figure 5.2: Of the 37 continent women, number of surgeries undergone before achieving continence. Although at the end of the research period, only 32 women in the sample were continent, 5 other women had recidivistic fistula, having experienced surgical success in the past, but developing a second fistula. Their experiences are accounted for here as well. In total, women underwent 74 operations, with an average of 2.0 ± 1.5 operations each.

Many women undergo one failed surgery after the next (sometimes as many as a dozen), spending years at the center (see chapter two).³⁴ Indeed, rather than representing a young cohort of women, recently crippled by the injury, 44% of my sample (who had undergone three or more previous failed surgeries at the end of the research period) represent a cohort of chronic sufferers.

Because the probability of surgical success is thought to be higher for women with no or only one previous surgeries (which will be discussed in greater detail below), the success rate for new cases is expected to be higher than the success rate for the entire sample. When looking specifically at surgical outcomes for “new cases” (defined as women who undergo one or two surgical interventions) in my sample, the surgical success rates are higher, but still lower than

³⁴ As discussed in chapter two, long wait times and prolonged stays at fistula centers are not unusual in Niamey. Harouna (2001) noted that only 20% of patients were at the Niamey hospital for less than 6 months, while 45.5% waited between 6 months and 1 year, and 34.5% of patients stayed for over a year.

expected. Of the 48 new cases, only 34 women received surgery during the research period. Of these 34 women, 18 of 34 (53%) attained continence, leaving the center dry, while 16 of 34 (47%) did not. When the outcomes of the remaining 14 new cases are included in success outcomes (using the data provided by women who were not looking for surgery during the research period regarding their continence and surgical history), the results remain similar: 21 of 48 new cases (44%) attained continence while 27 of 48 (56%) did not (see Table 5.2).

Of the 61 women who underwent surgery during the research period, 34 women (56%) were new cases, while 27 women (44%) underwent two or more previously failed surgeries before the research period. However, when looking at the breakdown of new versus old cases among the 22 women who attained continence during the research period, 16 (73%) of women were new cases while only 6 women (27%) were old cases. So, although among the 61 women in the sample, new versus old cases were about evenly split, nearly three-quarters of the women who gained continence during the research period were new cases.

Compared to the 80-95% success rates for fistula surgeries found in humanitarian and media literature, a 36% continence outcome appears notably lower. However, in comparing the data from available published studies on surgical outcomes for fistula procedures, these findings are not anomalous, but in fact, in the middle of the range of reported continence outcomes.

5.2 Surgical Outcomes for Niger-Based Studies

Rates of continence from my sample are comparable to published data from studies in Niger. Searching PubMed and several other databases in French and English for published findings on surgical outcomes from fistula interventions in Niger, I found a total of only thirteen studies (Table 5.3 and Figure 5.3).

ID	Author, Year	Sample size	Surgical Center	Population and/or Surgical Procedure	Outcome definition	Fistula Closure Percentage	Continence Percentage
1	Ascher-Walsh et al., 2010	140	HNN (Hôpital National de Niamey), Niamey	Women with residual incontinence (20% of all cases, N=701)	Post-operative continence	--	24
2	Barone et al., 2012	Not specified*	2 surgical centers in Niger (and 9 other centers in 5 countries)	Women with obstetric fistula	Fistula closure at 3 months post surgery	79**	60***
3	Falandry, 2000	49	HNN, Niamey	Women with residual incontinence	Post-operative continence	--	63
4	Issa Arzika 2011	40	Lamordé, Niamey	Women with obstetric fistula	Fistula closure, not specified	58	--
5	Maulet, Keita, and Macq, 2013	109	HNN and Lamordé, Niamey and Mali	Women with obstetric fistula	Post-operative continence	--	37
6	Nafiou et al., 2007	104	HNN, Niamey	Women with obstetric fistula	Fistula closure and continence	73	60
7	Onol et al., 2014	46	Niamey, not specified	Not specified	Not specified	83	--
8	Roenneburg and Wheeless, 2005	25	HNN and Lamordé, Niamey	Women with traumatic absence of proximal urethra (17% of all cases, N=180)	Fistula closure after primary procedure	57	48
9	Roenneburg, Genadry, Wheeless, 2006	73	HNN and Lamordé, Niamey	Women who have never received previous fistula surgeries	Fistula closure after primary procedure	56	44
10	Ruminjo et al., 2014	171	Two sites in Niger (n=74/97)	Women with obstetric fistula	Fistula closure at 3 month follow-up	60	49
11						66	25
12	Shaker et al. 2011	64	Lamordé, Niger (and Egypt)	A control and test group of women with fistula, one group undergoing "trimming" of fistula edges during surgery	Post-operative continence	--	75
13							67
14	Safan et al., 2009	38	Lamordé, Niger (and Ethiopia and Egypt)	Women with complicated fistula	Continence, 3 months post-op	--	63
15	Vanderputte, S.R., 1985	89	Dosso, Niger	Women with obstetric fistula	Fistula closure and continence	89	69

Table 5.3: Published findings from studies conducted in Niger on success percentages of fistula repair surgeries. *This study was conducted among 1,274 women in 11 sites in five countries, but the authors did not specify how many women came from Niger. **, *** These percentages were for the entire study and not specified by site or by country. Niger's closure and continence outcomes may have been higher or lower than the five-country average. Based on other published data from Engender Health's Fistula Care Project (with which this project was affiliated), I deduce that Niger's outcomes were lower than the project average.

The studies above are categorized by: sample size; surgical center; population; surgical procedure; outcome definition; and surgical outcome, including fistula closure and continence. The average sample size was 79 women \pm 45, and the majority of studies were conducted in Niamey. Closure percentages range from 57-89%, with an average of 69% \pm 12. The weighted average for closure (which accounts for sample size) is 67%. Continence percentages range from 24-75%, with an average of 53% \pm 16, and a weighted average of 45%. Between closure and continence percentages in these studies, there is a 16% difference and a 22% difference between the weighted averages.

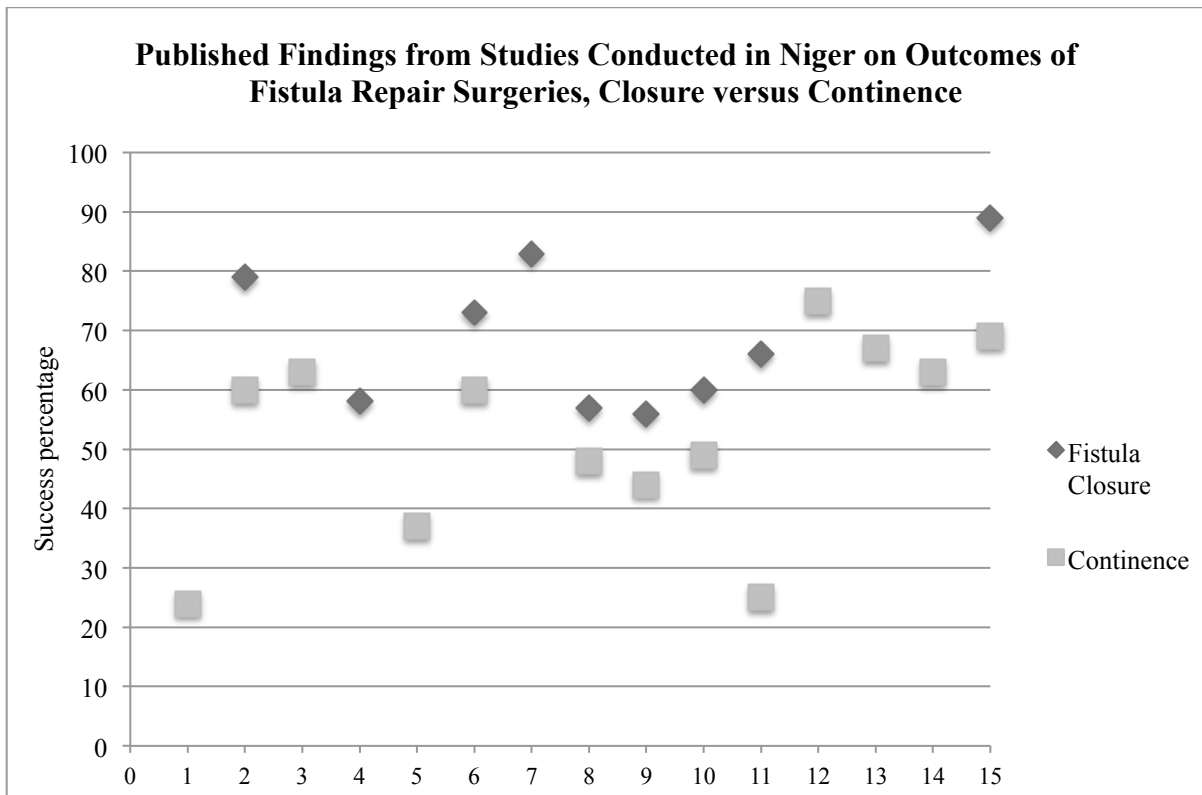


Figure 5.3: Published findings from thirteen studies (and 15 study ID numbers) conducted in Niger on outcomes of fistula repair surgeries. Fistula closure compared to continence (when available). Closure percentages range from 57-89%, with an average of 69% \pm 12, and a weighted average of 67%. Continence percentages range from 24-75%, with an average of 53% \pm 16, and a weighted average of 45%. Between closure and continence percentages in these studies, there is a 16% difference and a 22% difference between the weighted averages.

Clearly, the 36% continence outcome I found within my sample is markedly lower than success rates that are commonly reported in humanitarian and donor literature. However, when compared to continence percentages in other fistula studies conducted in Niger, my data do not appear anomalous. Yet, such poor outcomes are not frequently reflected in appeal publications of development agencies. As one (perhaps cynical) medical assistant working with women with fistula in Niger admitted: “The outcomes are much worse than they report—there is no accountability or incentive to produce real data here. No one wants the data.”

In the remainder of this chapter, I reconcile how modest success rates from studies can be systematically translated into higher success rates when deployed by invested actors and organizations. I investigate how surgical success rates of 80 or 90 percent are calculated, circulated, and understood as truth, representing a distinct form of knowledge creation.

5.3 Measuring Surgical Outcomes: Comparison Without Universal Categories

While much fistula literature emanating from donor and media sources report a relatively narrow range of expected outcomes, a handful of peer-reviewed studies suggest that surgical outcomes vary widely depending on the characteristics of particular fistulas or particular fistula characteristics. For example, Rathee and Nanda (1995) found success rates to range between 17% and 100% depending on particular defining attributes, or categorizations, of the fistula. Successful outcomes largely depend on factors that vary by case, including: the fistula size and location, degree of scarring and tissue loss, damage to the urethra, bladder capacity, prior surgical attempts, postoperative care, and the surgeon’s expertise and experience. Indeed, not all fistulas are the same, nor do they all have the same likelihood for repair.

While many of these characteristics are known to affect surgical outcomes, without an agreed upon system for classification, critical analysis of variance across studies is difficult.

Indeed, although there are more than 25 classification systems currently in use (most of which have been developed by individual surgeons and informed by their personal clinical experience), there is no international consensus as to which ought to be employed in research studies. Additionally, very few of the existing classification systems have been rigorously tested, and none has been proven accurate in predicting repair outcomes (Creanga and Genadry 2007; Frajzyngier 2011). This lack of standardized classification inhibits comparative analysis of treatment approaches and outcomes across studies. In the absence of an agreed upon classification system, researchers and clinicians may categorize fistula according to their type, anatomical location, size, involvement of other organs, degree of vaginal scarring, attachment of the fistula to the pelvic wall, condition of the urethral sphincter, location of ureteral orifices, and presence of complications such as abutting inflammatory lesions. Less detailed schemas of classification are sometimes employed, categorizing fistulas only by their extensiveness (single or multiple) or their complexity (simple or complex—although the classification of complexity is not standardized either).

The Illusive “Simple” Fistula: Basing the Rule on the Exception

Despite the problems posed by the lack of any agreed upon system to classify a fistula as “simple” (and thus the difficulty to compare between studies), simple fistula is frequently defined by some combination of the lack of previous failed surgeries, the lack of involvement of other continence mechanisms such as the urethra, and a measurement of less than three centimeters in diameter. Fistula surgeon Andrew Browning (2004b) defines a woman’s fistula as simple if she presents with “minimal vaginal scarring and a good bladder volume,” while fistula are classified as complex in cases with severe vaginal scarring (requiring some degree of vaginoplasty or vaginal reconstruction) or reduced bladder volume (due to bladder tissue loss)

(358). Genadry et al. (2007) define complex fistula as one that is “greater than four cm and involves the continence mechanism (the urethra is partially absent, the bladder capacity is reduced, or both); is associated with moderately severe scarring of the trigone and urethrovesical junction; and/or has multiple openings” (S51). Additionally, many clinicians note that when a fistula surgery fails, a formerly simple fistula may become complex due to the scarring caused by the failed surgery. Despite the ambiguity surrounding the exact meaning of “simple” fistula, there is wide agreement that “simple” fistulas are more likely to have good surgical outcomes.

Although a 90% success rate is widely cited (and infrequently achieved), authors sometimes do specify that only 90% of *simple* fistulas can be cured through surgery. For example, Ndiaye et al. (2009) explain that surgical intervention is successful for 90% of “the simplest cases” (61). Similarly, Creanga et al. (2007) suggest that closure rates of “simple” fistula range between 70% and 90%, dropping to between 30% and 60% for “complex” fistula. That “90% of simple fistulas” is then misunderstood, misrepresented, or misreported as “90% of [all] fistulas” in donor and media reports is a good example of what Best (2001) calls “mutant statistics,” distorted versions of original figures often born from deliberate attempts to distort information in order to strengthen claims. These donor and media reports, however, are then used and cited in academic literature—reifying these truth claims and creating new forms of knowledge (for example see Miller et al. 2005 who cite the UNFPA to make a 90% surgical success claim).

Yet, many researchers agree that the majority of fistulas in sub-Saharan Africa are probably not “simple.” According to Genadry et al. (2007), “Obstetric fistulas are rarely simple. Most patients in sub-Saharan Africa and parts of Asia are carriers of complex fistulas or

complicated fistulas requiring expert skills for evaluation and management” (S51). The authors highlight the relative rarity of “simple” obstetric fistula:

Lucky is the patient who presents with a small communication, less than 2 cm in diameter, above the vesical trigone and far from the urinary continence mechanism, because her fistula is easily accessible and has minimal scarring. Most likely, in both the developed and developing world, such a fistula is iatrogenic and follows a cesarean section or hysterectomy. In sub-Saharan Africa and parts of Asia, most patients who present with obstetric fistulas are not so fortunate... These patients are often carriers of complex and/or complicated (> 6 cm) fistulas requiring expert skills for evaluation and management. Although the data on the true distribution of simple and complex VVFs are inadequate, more than 70% of obstetric VVFs are reported as complicated. (Genadry et al. 2007: S51)

If Genadry is correct, then despite the ubiquity of the 90% closure estimation for simple fistula, less than 30% of women have fistulas that could qualify for such optimistic estimations. Indeed, many studies, particularly those conducted in Niger, note that only a very small proportion of women in research samples had what might be classified as a “simple” fistula. For example, a study conducted in Niger by Cam et al. (2010) found that a vast majority of women in their sample had “complex” fistula while less than 20% of cases could be classified as “simple”:

80.4% had fistulas greater than 4 cm and/or trigonal-urethral involvement and/or severe scarring reducing vaginal or bladder capacity. Some 66% of patients had experienced previously failed repairs. Only 19.6% of fistulas were primary, less than 4 cm, and not involving any adjacent structure. (Cam et al. 2010: 294)

In another study conducted in Maradi, Niger by Karateke et al. (2010), 60% of women had a fistula greater than four cm in size, the urethra was circumferentially lost among 16%, 20% had extensive scarring; 10% had severe infection, 10% had multiple fistulas, and 67% had undergone at least one previous fistula surgery. Only 22% had neither obliterating scarring nor urethral damage. In other words, 78% of Karateke’s sample had complex fistula. In Falandry’s sample of 49 fistula patients in Niamey, Niger, 35% had what he classified as “Group 1,” or simple, fistula while 65% of patients had Group 2 or 3, or “complex,” fistulas (Falandry 2000). Based

on the available studies conducted on fistula in Niger, it can be extrapolated that the majority of fistula cases seen in Niger are not “simple.” So, while estimates for surgical success are often premised on “simple” fistula, in reality, these cases represent the minority of Nigerien women.

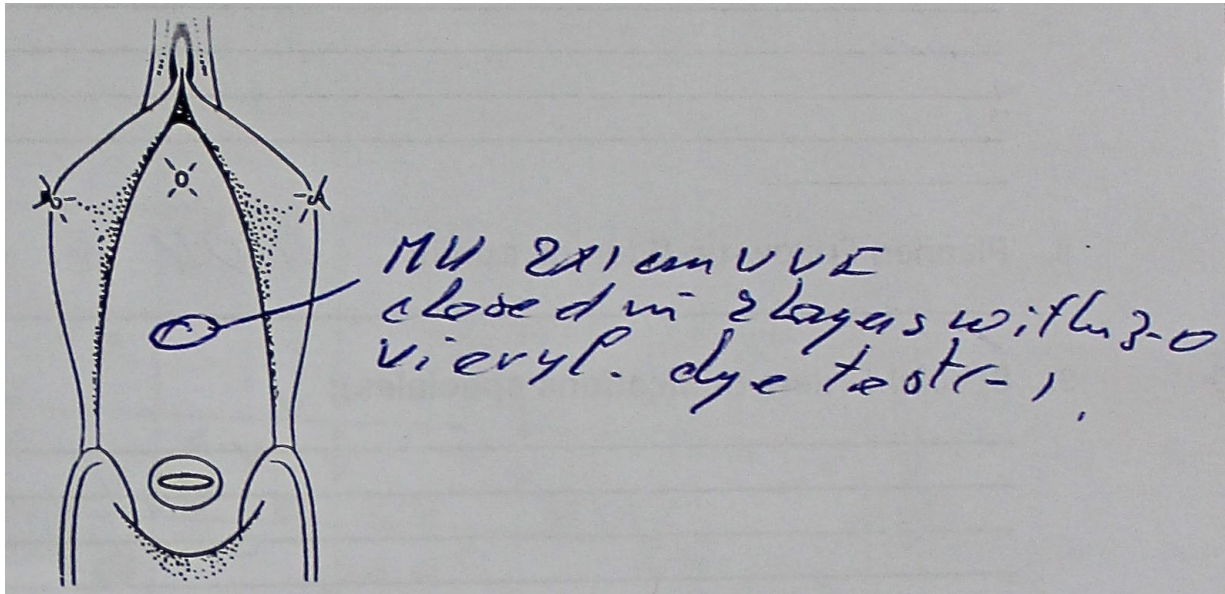


Figure 5.4: The clinical file of a woman with a “simple,” small fistula measuring 2 x 1cm. This fistula was closed surgically and the woman was negative in her dye test, meaning that no liquid leaked from the fistula (or, that she was continent). Simple fistula may represent the minority of fistula cases in Niger.

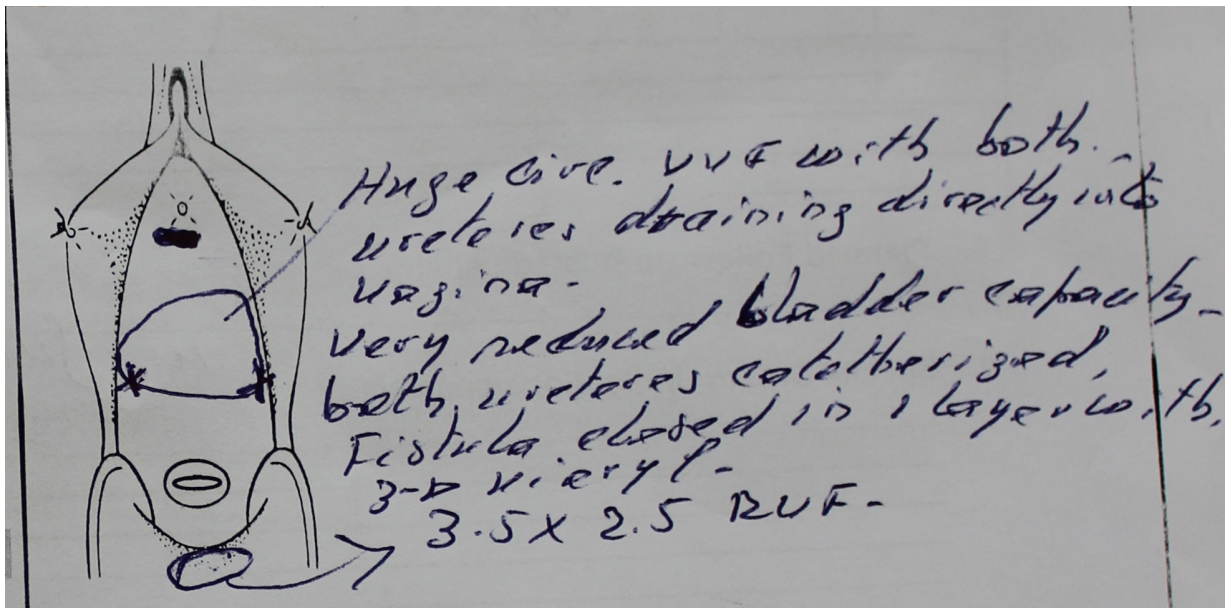


Figure 5.5: The clinical file of a woman with “complex” vesico-vaginal and recto-vaginal fistulas who developed fistula following her ninth pregnancy. She had undergone three previous unsuccessful surgeries. The picture above notes that she had a “huge circumferential VVF with both ureters draining directly into the vagina,” “Very reduced bladder capacity,” and a large RVF measuring 3.5 x 2.5 cm.

Surgical Success for “New Cases” and the Effect of Previous Surgeries

Like cases of “simple” fistula, women with no previous history of fistula repair, known as “new cases,” are thought to experience much higher rates of surgical success due to the presumed lack of scar tissue. Holme et al. (2007) found that the failure rate of surgery increased three-fold for “old cases,” or women who had experienced one or more previous repair attempts.³⁵ In an 18-month cohort study conducted with 120 fistula patients in Mali and Niger, Maulet, Keita, and Macq (2013) found that “new cases,” which they defined as women having received one or no previous failed fistula surgeries, had a success rate of 74% (23/31) (success being defined as closure *and* continence) with a mean of 1.5 surgeries. However, only 22% (17/78) of “old cases” (defined as women with two or more previously failed surgeries) attained continence with a mean of 4 surgeries. Although these percentages are not clearly presented, the total success rate can be calculated as 40/109, or 36.7% success—a striking deviation from the 90% often-cited success rate. Additionally, in this study “new cases” represented only 28% (31/109) of women, while 72% (78/109) were “old cases,” meaning that the vast majority of their sample had already undergone previous failed surgeries (at recruitment, old cases had undergone a total of 299 previous surgeries, or an average of nearly 4 previous surgeries each) (Maulet, Keita, and Macq 2013). The authors report a 37% closure and continence rate for their study, stressing that, “the quest for continence does not end with admission to a fistula center” (Maulet, Keita, and Macq 2013: 524). The authors conclude:

Our results emphasize the negative outcomes of some women who underwent fistula repair. Negative outcomes are not frequently reported in the literature. We believe that this is due to a strong bias towards positive outcome reports... However, publication of negative results should be encouraged to grasp [the] reality of fistula repair process and outcomes. (532)

³⁵ There is also a lack of consensus regarding the definition of “new” versus “old” cases, with some clinicians defining old cases and women who have undergone one or more previously failed surgery, and others defining old cases as women who have undergone two or more previously failed surgeries.

Roenneburg, Genadry, and Wheelless (2006) examined the success rates for women who underwent fistula repair in Niamey, Niger. They sampled only new cases and found that after a primary repair of 73 women, 41 women had fistula closure. However, 9 of these women (22% or 9/41) had continued stress incontinence, mixed incontinence, or detrusor over-activity. If success is defined as closure *and* continence (arguably a more accurate definition, which will be discussed in more detail below), then the success rate falls further, leading the authors to warn:

Many authors have reported successful fistula repair in 90% of their primary repairs, and this percentage has been held as the standard for all fistulas operations. Our series fails to confirm this success rate and raises many questions. When all patients, regardless of the size and location of their fistulas, are offered surgical repairs, success rates fall far below this perceived success rate of 90%. In this series, the primary repair rate when we operated to repair all types of fistulas was 41%. The primary repair is considered the best chance of success. Failed repair is a risk factor for the worsening of the prognosis of subsequent repairs. Failed repairs may occur in patients with more severe scarring and neurologic damage; each repair adds to the scarring and neurologic damage. (Roenneburg, Genadry, and Wheelless 2006: 1751)

Roenneburg, Genadry, and Wheelless (2006) argue against the widely reported 90% success rate of fistula surgery, reporting a success rate of 41% of new cases which, (had they calculated the success rate of all operations, even those performed on women with a history of failed surgeries) would have been invariably lower.

The vast majority of researchers and clinicians agree that the risk of surgical failure increases with the number of previous surgical attempts (Arrowsmith, Barone, and Ruminjo 2013; Cam et al. 2010; Castille et al. 2014; Creanga and Genadry 2007; Karateke et al. 2010; Maulet, Keita, and Macq 2013). Arrowsmith, Barone, and Ruminjo (2013) claim that, “In Niger, prior surgery significantly predicted reduced success... ‘surgical success’ . . . was reduced by nearly two-thirds for women with prior repeat surgery. A large multi-country cohort study found that prior repair independently predicted failed fistula closure and residual incontinence” (5).

Karateke et al. (2010) assert that, “The first repair of obstetric vesicovaginal fistulas affords the

best success rate and a fistula with graver prognosis is created when repair fails. The number of previous repair attempts is reported to be an important factor for a successful surgical closure of OF [obstetric fistula]" (255). Cam et al. (2010) claim that, "A simple fistula may become complex when repair fails. The number of previous repair attempts is reported to be an important factor for a successful closure and the first repair affords the best success rates" (Cam et al. 2010: 295).

Additionally, as demonstrated above, Roenneburg, Genadry, and Wheelless (2006) calculated a 56% surgical success rate when operating on new cases. However, when women whose primary operation was not successful underwent a second operation, the success rate dropped to only 43%. Of those women who then went on to receive a third surgery, none of their fistulas were successfully closed. Although their sample size is quite small, their findings suggest dramatic implications for repeat surgeries.

Finally, Maulet, Keita, and Macq (2013) found among women in Niger and Mali that, "Continence gain was statistically associated with the number of fistula surgeries already undergone. Old cases had a 3.4 times smaller chance to gain continence than new ones, and the total duration of care to gain continence was significantly higher for old cases than for new ones: a median of 4.9 years vs. 0.6 years." They conclude that new cases "stand a good chance of rapid continence gains" while old cases "cling to hope" (Maulet, Keita, and Macq 2013: 531).

The stark difference between surgical outcomes of new versus old cases significantly impacts predicted success rates among women with fistula in Niger. A study of the demographics of women with fistula in Niger conducted by UNFPA and Niger's Ministry of Health in 2013 (in which all 176 women at the six State-run fistula repair centers in Niger in April 2013 were sampled) revealed that only 24 women (13%) had never undergone fistula

surgery while 47 women (26%) underwent one previous failed surgery and 33 women (19%) underwent two previous failed surgeries. However, 74 women (42%) had undergone between three and ten previous failed surgeries (Doudou 2013). In presenting these data at an international fistula conference, Dr. Hassane Doudou critiqued that women had “often experienced many interventions without success... The multiple operations indicate the need to ameliorate the quality of interventions at the centers” (Doudou 2013). In this light, it is reasonable to expect success rates for fistula repair in Niger to be significantly lower than 90%.

5.4 The How and When of Defining Success

In peer-reviewed medical journals, estimates for surgical success of fistula repair surgeries vary, ranging anywhere from 17% to 95% (Maulet, Keita, and Macq 2013; Arrowsmith, Barone, and Ruminjo 2013). While some of the variation may be accounted for due to differences in surgical skill (a variable which, not surprisingly, is not reported nor measured),³⁶ I contend that much of the variation can be explained by the methods through which “success” is defined and measured. Along with the lack of a standardized system of classification that can determine the severity of a patient’s injuries, there is also a lack of consensus regarding what constitutes a “successful” surgical outcome. There is ambiguity surrounding both *how* and *when* success should be measured. Should success be defined as surgical closure of a fistula, urinary continence, improvement, or the return to normal sexual functioning? Should success be measured directly following fistula surgery, the next week, the

³⁶ Varying surgical skill and experience may very well mediate differences in surgical success outcomes. Much of the data emanating from the Hamlin Hospitals in Ethiopia (the largest and longest running center devoted strictly to fistula repair) suggests markedly higher rates of success than fistula centers elsewhere. Additionally, as fistula has attracted Western attention, Western medical practitioners have begun partaking in brief medical missions to the Global South to operate on women with obstetric fistula. Termed somewhat pejoratively “fistula tourism” (Wall et al. 2006), these clinicians are thought to lack the necessary training and experience to execute fistula surgeries well, often rendering poor surgical outcomes.

next month, or after three months? Because there is no universally agreed upon criterion for how and when to measure “success,” the surgical success outcomes of studies are often not comparable.

What to Measure: Defining Success by Closure Versus Continence

Many authors report “success” as “the surgical closure of the fistula at the time of hospital discharge” (Creanga and Genadry 2007: S44). However, following a fistula surgery, a woman’s fistulas may “successfully” be closed, yet she may still leak urine. In such a case, many women may be counted as successfully repaired while still “wet” or incontinent. Persistent transurethral urine loss can be caused by many factors, including: the loss of bladder capacity, compliance, sensation, motor innervation; coordination between bladder and sphincter; urethral length; or sphincter disruption or destruction (Arrowsmith, Barone, and Ruminjo 2013; Wall and Arrowsmith 2007). Researchers estimate that anywhere between 26 and 55 percent of women whose fistulas have been surgically closed will suffer from residual incontinence (Arrowsmith, Hamlin, and Wall 1996; Frajzyngier 2011). Browning (2004b) reviewed 318 consecutive fistula patients admitted to Addis Ababa Fistula Hospital in 2000 and found that despite successful closure of the fistula, 50% of women with “simple” fistula, and 100% of women with “complex” fistula experienced immediate post-operative residual incontinence:

Patients with low vaginal fistulae can be divided into two groups, which appears to influence outcome with regards to post-operative residual incontinence. The groups are those with simple fistulae, with minimal vaginal scarring and good bladder volume, of whom from the series of 318 patients, 50% develop incontinence, and those with more complex fistulae with severe vaginal scarring and/or reduced bladder volume, of whom 100% will develop incontinence in the immediate post-operative period. (Browning 2004b: 360)

Similarly, in their 2007 article, Wall and Arrowsmith contend that the community of fistula surgeons must make steps to improve data collection and reporting. Wall and Arrowsmith

argue that, “patients want more than just having holes in their bladders closed” (843). In order to address this “continence gap,” clinicians must report the “true outcomes of attempted fistula repair operations,” reporting on continence, not just closure (Wall and Arrowsmith 2007: 844). Wall and Arrowsmith go further, suggesting that “success” might not only be redefined in order to address the “continence gap,” but also to address (and systematically record and report on) other unaccounted for (and thus too often invisible) problems of fertility and sexual functioning faced by many women with fistula.

Indeed, depending on the severity of both a woman’s fistula before surgery and the severity of residual incontinence after surgery, women might experience very little difference between a closed fistula with residual incontinence and an unrepaired fistula. As Castille et al. (2014) explain, “For women whose fistula is closed but who remain incontinent the situation remains unsatisfactory and these women often do not see the benefit of a closed fistula” (Castille et al. 2014: 80).

During the research period, several women in my sample who underwent successful surgical repairs (but also experienced some form of residual incontinence) did not believe that their fistulas were closed. Some women did report improvement, many of whom explained that they were now capable of holding their urine for between a few seconds to a few minutes, allowing themselves time to make it to a toilet (and thus greatly improving their quality of life). However, many others experienced persistent incontinence that was so troublesome that even though their fistulas were closed, there was no significant change in their quality of life. Indeed, for many women it was not until I consulted her clinical file or practitioner that I would learn that her fistula was “cured,” defined by centers by fistula closure. Because most centers do not adequately explain to women what a fistula is and how it affects continence, they understand

fistula only as a disease that causes persistent incontinence (rather than a discrete injury to the bladder that creates a hole through which urine leaks out). So, if a woman no longer has fistula but continues to experience incontinence, she may neither perceive nor comprehend a difference in her condition. Even the Hausa words for obstetric fistula, *ciwon yoyo fitsare*, or “illness of leaking urine,” does not differentiate between a physical hole in the bladder versus other causes of incontinence. Women do not know if they are leaking urine due to an abnormal connection between their bladder and vagina, or because of reduced bladder size, or urethral weakness. For these women with residual incontinence, many considered their surgeries as failures, and either refused to leave the fistula centers, returned to centers to pursue additional surgeries, or travelled to other fistula centers hoping for a better result.

During my time in a Niamey fistula center, I spoke with Salamatou, a fifty-five-year-old Fulani woman, outside of the operation block. She sat under a tree with an IV needle still coming out of her hand. “When I was in the operating room, the doctor said he couldn’t find the hole. So, he told me he couldn’t operate. I don’t know what I am to do now,” she told me, visibly upset. Twenty-seven years before, Salamatou believed that she developed a fistula after a long and painful labor. Although she never sought biomedical intervention, after a year of interventions from the local herbalist, her leaking diminished and ultimately disappeared. But two years ago, Salamatou’s leaking returned. Salamatou was devastated by her incontinence, which she said greatly impacted the quality of her life:

Many people will not eat with a woman who leaks urine. Many gossip about me—“*fitsare gare ta*,” she has urine, they say. The urine, it smells. People cover their noses when I am around. When they do this, it is as though they are asking me to leave. Some say that Allah is punishing me. Some insult me, calling me worthless... [This mistreatment] only started with the sickness. I feel ashamed, but what can I do? I am not well. I am leaking.

When I asked Salamatou how her illness affected her identity, she explained, “With fistula, I can’t think about being a woman, I am not even a human anymore.” When I spoke with the surgeon who had examined her, he shrugged, explaining, “She doesn’t have a fistula. Maybe it is an infection?” Indeed, it is not the physical hole that matters to women. It is not the hole that determines their illness experience. What matters are the symptoms, and if a woman’s hole is closed, but her incontinence persists, depending on the severity, she may not experience a marked difference pre- and post- closure.

When to Measure: Capturing Repair Breakdown

Due to the heavy reliance on visiting surgical missions (and thus the impossibility of follow-up), as well as other factors (including the incentive to produce high success rates and the lack of resources restricting the possibility for follow-up), many researchers and clinicians define success as the closure of the fistula immediately following a repair surgery. Often, a methylene blue dye test will be performed on the patient while she is still in the operation block. If the dye does not exit through the fistula, she may be defined as successfully closed. However, these women who are counted as successes have a high chance of suffering from residual incontinence, or of experiencing a fistula closure breakdown during the postoperative period.

In a study conducted on first-time fistula cases in Ethiopia, there was a 10% repair breakdown between the intraoperative dye test and a second dye test performed 14 days postoperatively, demonstrating the artificially inflated success rates for studies which measure dryness directly following surgery (Raasen, Verdaasdonk, and Vierhout 2008). Similarly, 14 days following fistula repair surgeries, Murray et al. (2002) found that 100% of the 55 women in their sample who had undergone operations were continent. However, at an eight-week postoperative follow-up, 30 women (55%) complained of persistent urinary incontinence while

21 (38%) complained of altered fecal incontinence. Thus, this study highlights both the importance of *when* measurements are taken (immediately after surgery, two weeks, or two months, for example) and *what* is being measured (closure or continence) is producing drastically different “success” outcomes.

I asked an African fistula surgeon who was visiting Niamey as part of a surgical mission about surgical success rates. He explained the difference in measuring surgical success for simple and complicated fistula, but also explained the importance of when success is measured:

In good conditions, for simple fistula, surgical success is almost 100%. But, for other fistulas, maybe it is 75%. In my experience, if the center is well equipped and has good staff, the cure rate is always raising. The problem is that people think that the failure or success depends only on the surgeons. That is why we have an immediate success rate. After the surgery I do a dye test. If there is no dye leaking, I count it as a success. But, in truth, outside of the [surgical] block, 50% of the operations fail.

I argue that defining success either as surgical closure (rather than continence), or measuring success directly following surgery, is misleading as both rubrics for success may fail to reflect long-term continence from women’s experience. This tendency to measure success as closure, or to measure success early, reflects the tensions created within a field that has not yet been entirely professionalized. As a result, clinical outcomes may be interpreted in various ways, with incentives to translate data into pieces of marketing. During an interview with a head nurse who ran much of both the clinical and administrative sides of a Niamey fistula center, I asked about how “success” was measured. He acknowledged that the current method of measuring success was problematic: “For the surgeons, I think that when they operate, they do a dye test and if there isn't a visible leak, they count the operation as successful. But two or three days after, the women leak. I believe that the women should be evaluated after 14 days, but it isn't done this way and it isn't my choice.”

5.5 Tricky Math: Interrogating the Data and Redefining Success

In addition to the ‘how’ and ‘when’ of success measurement, another way in which success rates can be manipulated to serve particular interests is through the method by which success rates are calculated. After calculating the success rate for my sample, I became worried about the low rates of success (or, continence) within my sample. Throughout the process, as my sample grew, my success outcomes remained constant, fluctuating only slightly between 35 to 38%. I met with a data manager who worked for the State’s fistula coordination network. He was partially responsible for calculating and reporting national success rates, which varied slightly, but appeared not to drop below 72%. In an attempt to reconcile my own findings with discordant national data, I asked him to walk me through his calculations.

In the calculation of a percentage, there is a numerator and a denominator—a subset divided into a whole—in the calculations of success rates, “successful” cases are the numerators, and total cases are the denominators. In the previous sections I have discussed the ambiguity in determining the numerator, suggesting that external pressures to produce “better data,” or higher rates of surgical success, along with the lack of international standardization, result in an artificially inflated numerator, or, the number of women considered “successes.” The data manager at REF suggested that there was another way to inflate success outcomes: by deflating denominators, or decreasing the number of total cases.

First, rather than dividing the number of “successful” surgeries by the total number of surgeries, they can be divided by the total number of women who leave the center each trimester. From my experience at centers in Niger, women who do not attain continence following surgeries frequently do not leave the center, opting instead to wait on the hospital grounds for the next round of surgeries. So, this method of calculating success renders a large proportion of

chronic suffers and surgical failures statistically invisible. A second method to deflate the number of total cases, and thus inflate total success rates, is to exclude complex cases from operations, also rendering them statistically invisible.

Finally, success outcomes are inflated through the manipulation of the denominator by defining the total caseload by the number of women receiving operations, rather than by the number of operations performed. As many women receive multiple surgeries within a year, calculations based on the number of women (rather than operations) can be highly problematic. For example, if a woman receives four surgeries within a year, the first three of which are unsuccessful, but the final surgery succeeds and results in continence, calculations based on surgeries would yield a success rate of 25% (one surgery resulting in continence divided by four total surgeries). However, many researchers opt to calculate success based on women (in this example, one surgical success divided by one woman), yielding in this example a success rate of 100%. If this approach is adopted in conjunction with an approach classifying success as closure rather than continence, then this same woman could undergo four surgeries, still be incontinent but pass a dye test indicating fistula closure, and still reflect a 100% success rate.

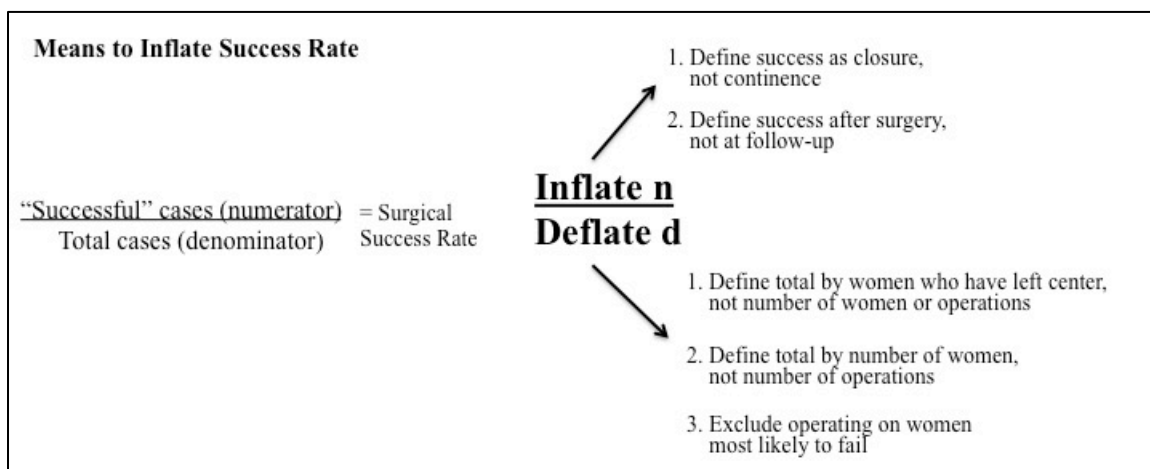


Figure 5.6: Model of methods commonly used to inflate success rates, the first of which rely on inflating the number of “successful” cases in the calculation, and the second approach (which may be used alone or in conjunction with the first approach) shrinks the number of total cases in the calculation.

For example, Amr's (1998) study reports an 82% success rate. However, when the data are probed, the success rate of surgeries (rather than what the author refers to as "cases," or, women) is much lower. Out of a sample of 132 cases, Amr states, "Successful repair of 108 cases was achieved (82%), 60 cases of them from the first attempt (45%) and, 48 other cases after repeated attempts (36%). In 24 cases, a total of 72 repeated operations failed" (1998: 202). Without knowing exactly how many surgeries the 48 women required before achieving closure, we can calculate an upper bound for success rate by assuming that each woman received at most two surgeries. Assuming a lower bound of 228 total surgeries renders an upper bound on successful closure rate of 47%. Additionally, Amr does not specify what success means nor when it was determined. Still, articles that cite this study reference an 82% success rate.

Yet, some professionals claim that counting success by individual women rather than by operation is a more important measure, arguing that what ultimately matters is not how many surgeries it took to for a woman to gain continence but that she ultimately did achieve continence. However, this method leads readers and funders (and women themselves) to dismiss the complexity of fistula treatment seeking and the necessary amount of time and resources involved for women, practitioners, and clinics.

Indeed, in the fistula narrative, the low cost of fistula surgeries is often highlighted. While the cost of fistula surgery is often much higher than the \$300 or \$450 often quoted,³⁷ the price becomes several times higher when failed surgeries are not accounted for. If it took a woman four surgeries to gain continence, even at the (arguably) misleadingly low price of \$450 a surgery, it would still have cost \$1,800 to render her continent (and even more if her lost productivity at home is calculated). According to Maulet, Keita, and Macq (2013), of the

³⁷ \$300 is said to be the cost of fistula surgery in Niger according to the UNFPA (UNFPA, n.d.). \$450 is quoted as the price of fistula surgery at Fistulafoundation.org

women in their sample who achieved continence, it took an average of 1.5 surgeries for new cases and 4 surgeries for old cases. Thus, the actual cost of continence would be an average of \$675 for “new cases” and \$1,800 for “old cases.” Then the misleading cost and the length of time required for a woman to wait at a center is also overlooked, and thus the consequences of her prolonged absence from her home and social networks are rendered invisible.

The former Executive Director of the Worldwide Fistula Fund (the non profit organization that runs the Danja Fistula Center) explained to me that the real price of surgeries was highly underestimated:

How do we deem success? Some people call a surgery successful if the hole is closed—but there isn’t follow up—they don’t account for incontinence or if a week later the suture doesn’t hold and you are back to square one. When I write grant applications I say that the cost of surgery is \$1,700 USD—that’s the real cost, including staffing and supplies, which by the way, we get for very cheap. We are very frugal, but that is how much it actually costs.

Considering that women in my sample underwent between one and eleven surgeries (with an average of 2.8 surgeries each), if \$1,700 per surgery is closer to the reality than \$450, surgical intervention for the average woman costs \$4,760 but as much as \$18,700. Admittedly, a center like Danja would probably never continue to operate on a woman who had undergone ten previous operations (although an agreed upon national or international standard for deeming a woman “incurable” or “inoperable” does not exist), and it might be the case that other centers are able to provide interventions more cheaply than Danja. However, according to IRIN, a service of the UN Office for the Coordination of Humanitarian Affairs, one fistula operation in Niger costs “upwards of 1 million CFA francs (US\$2,100)” (IRIN 2007), making a surgical intervention for the “average woman” cost more than \$5,880 (and potentially as much as \$23,100)—a far cry from a purported \$300 or \$450 quick-fix.

Although these cost estimations are not definitive, the general point remains that fistula surgeries are neither as straightforward nor as inexpensive as advertised. As half of women (50%) who were cured of fistula were cured after their first intervention, but women underwent an average of 2.8 surgeries each, there is arguably a large economic loss (\$3,060). Considering that the average amount of money spent on healthcare per person a year in Niger is only US\$25 (one of the lowest in the world—compared to almost US\$9,000 in the United States) (WHO 2012),³⁸ and the general poor state of the Nigerien health care system as a whole, looking at the actual cost of fistula surgeries forces us to evaluate if limited economic resources are making the greatest possible impact in the realm of maternal health in Niger. Fistula surgeon Rene Genadry, who frequently participates in surgical missions in Niger, wrote a letter expressing a similar concern, questioning if fistula surgery was the best utilization of resources: “One gets the impression that what one is doing is but a drop in the ocean of misery, and resources could be better spent on prevention, education and more essential care. But in the meantime one realizes that there are human beings that are suffering emotionally and physically from lack thereof and need a helping hand today and now” (Genadry 2012: 3). Yet, these questions of medical ethics and resource allocation cannot even be asked when a woman’s surgical history is rendered invisible within the statistical calculations.

Finally, women with the most complex surgeries are often not operated on and thus left out of the calculations entirely. Twenty-six women in my sample did not receive surgery for the duration of the year-long research period. Although the reasons for this varied by woman and by center, many of these women suffered from complex fistula. During my research, in preparation for an upcoming foreign surgical mission, women with fistula were screened at a Niamey center.

³⁸ According to the WHO, total health expenditure is the sum of public and private health expenditures as a ratio of total population. Included are the provision of health services, both preventive and curative, family planning activities, nutrition activities, and emergency aid designated for health.

Fanta, a Kanuri woman from the border of Chad (who did not speak Hausa or Zarma and thus was unable to communicate with clinic staff except through the occasional use of another patient who could translate) had been waiting several months for surgery. When she was examined by the clinical team that prepared the dossiers for women who would be selected for surgery, she was told that she would not be chosen for surgery during this mission. The head nurse explained that, “Her vagina is too damaged. There are scars and there isn’t much tissue left. She might need a blood transfusion, which we can’t do here.”

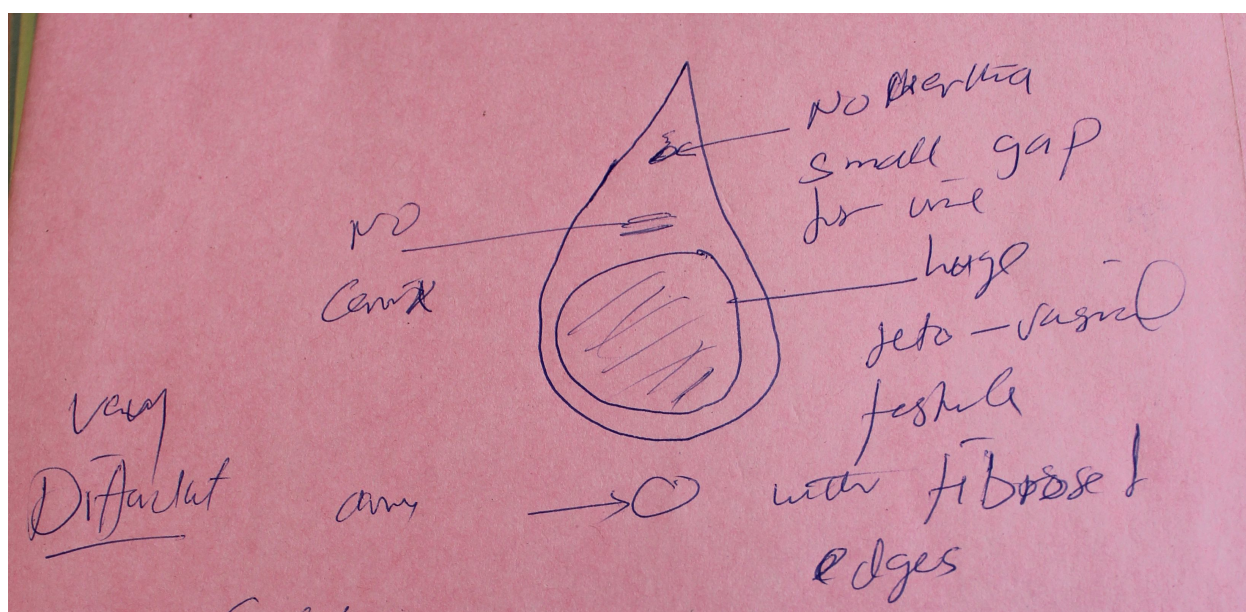


Figure 5.7: The clinical file of a woman with complex fistula (who was continually excluded from surgical repair missions due to the difficulty of her case). Her file indicates, “no cervix,” “no urethra,” and “huge” fistula with scarred edges. At the edge of her file is written “very difficult.” This file is not dissimilar from those of other women who were repeatedly skipped over for surgery.

I witnessed many women like Fanta who were excluded from the surgical queue due to extensive damage (and due to reasons unrelated to the extensiveness of damage, such as menstruation at the time of surgery)—despite the fact that at least two of these centers considered themselves “centers of excellence” for complicated cases. Indeed, women like Fanta were systematically excluded from operation blocks as surgeons demonstrated a preference for women with no previous surgeries and for women with “simple” fistula. As a result, surgical

success rates in Niger (and potentially elsewhere) may be skewed, artificially inflated as the most difficult cases become clinically invisible, lingering for months and years on centers' grounds without ever making it into the operation block and thus into the official statistics.

After speaking with the REF data manager for over an hour, tenaciously pushing him on his methods of data calculation (blurring the line between ethnologist and investigative reporter), he called over the head nurse from a fistula center who was there to submit a quarterly report. Before stepping away, he asked the nurse to read to me her report. It read: Twenty-two women looking for surgery; 21 of whom received surgery (one woman treated with a catheter). Six women were classified as new cases (undergoing their first surgeries), while eight more underwent their second surgeries. The remaining eight women had already undergone three or more previous failed surgeries. Out of the 21 women who received operations, eight were dry and closed, while twelve were not. I pulled out a calculator and divided the eight successes by twenty-one, rendering a success rate of 39%. When the data manager returned to the table, he said to me: "Trust your data. Stay faithful to them."

As I continued my quest to understand my data, I spoke with a social worker at a Niamey fistula center who confided in me that out of the 74 surgeries performed by a recent visiting surgical mission, only 10 women were continent. When I expressed my surprise, she responded that ten successes were, "already good." "Sometimes they do fifty surgeries without a single successful case," she told me. Her admission of poor surgical outcomes signifies something of greater importance, that those closest to fistula repair are forced to reconcile their observations of frequent repair failure with a hegemonic discourse positioning surgical intervention as highly efficacious—a discourse that is vital to ensuring the continued funding of fistula work.

The 90% claim is tenacious, even when challenged by actual outcome data.

Organizations often creatively deploy data generated from studies in order to tell particular narratives. Humanitarian organizations compete for donors and reporters compete for readers, and not only are victims presented as more and more pitiable, but solutions must be ever quicker, easier, and more effective. Humanitarian organizations capitalize on the ambiguity surrounding fistula categorization and outcome measurement to transform data to better align with the narrative of surgical redemption. The media then tend to report and reproduce humanitarian organization's claims of high success rates, rather than clinical studies more modest outcomes.

This tension between clinical findings and the transformation of data into packaged, general, advertised success rates is apparent with the Nigerian NGO Dimol, which frequently discusses women with fistula in their triannual newsletter, publicizing their work in the domain. In a 2004 newsletter, Dimol claims that the success rate for a woman who has never been previously operated on is *guaranteed 99%* (Dimol 2004). However, Dimol's data from the previous year (published in a 2003 triannual newsletter) belies such a strong claim. In 2003, the organization published that 86 women with fistula were consulted by Dimol, 67 of whom were operated on for fistula. Of these 67 women, only 18 were healed—a 27% success rate (Dimol 2003). Yet, a 27% success rate did not temper Dimol's claim the following year, when surgical success was “*assuré*” (or assured) at 99% (Dimol 2004).

5.6 The Ubiquity of Bad Data and “Mutant Statistics”

Instead of imagining that statistics are like rocks, we'd do better to think of them as jewels. Gemstones may be found in nature, but people have to create jewels. Jewels must be selected, cut, polished, and placed in settings to be viewed from particular angles. In much the same way, people create statistics: they choose what to count, how to go about counting, which of the resulting numbers they share with others, and which words they use to describe and interpret those figures. (Best 2004: xii —xiii)

For decades social theorists have argued for a more critical approach to numbers, indicators, and statistics that have played an increasingly important role within the production of knowledge. Scholars argue that techniques of enumeration have clear relationships to power, demanding certain kinds of things or people to count while others are rendered invisible (see Hacking 1990).

Organizations frequently deploy statistical “facts” as rhetorical tools that do the invisible work of the organization—channeling public attention (and ideally resources) of specific issues. The production and reification of truth possible through the utilization (and manipulation) of numbers is evident not only when examining reported surgical success rates, but also the estimated incidence and prevalence of fistula. Within peer-reviewed articles, informational websites, the Demographic and Health Surveys, and non-profit organizations’ materials, it is most commonly cited that two million women suffer from fistula with an additional 50,000 to 100,000 new cases each year. Although many authors concede that the numbers estimating the magnitude of obstetric fistula are poor and extremely difficult to determine, these prevalence and incidence figures are pervasive and infrequently contested. In their ubiquity, these figures have what Feingold (2010) calls “numerical certainty” and “statistical doubt”—claiming with confidence (and little variation) unsubstantiated (and potentially untrue) numbers.

In an attempt to locate the genesis of these statistics, I traced the citations of 80 articles that made claims regarding fistula prevalence and incidence to their original sources. The standard claim of 2 million women with fistula and 50,000 -100,000 new cases a year was made in 88% of the articles. In support of this claim, 30% of the 80 articles cited the WHO, 20% cited articles written by Dutch surgeon Kees Waaldijk, 15% cited the UNFPA, and 13% offered no

citation at all.³⁹ Although a large proportion of articles cite various WHO or United Nations working group papers, publications, or websites to support their prevalence and incidence claims (couching the estimates in a veil of authority), neither organization has conducted any original epidemiologic research or presented well documented methods in order to support the claim.

The earliest cited source for the 2,000,000/50,000-100,000 estimation is a 1989 WHO Technical Working Group Paper (forty-two percent of all papers that cited the WHO cited this particular paper). However (after a lengthy process to locate the obscure document held only by a handful of libraries in the world), the paper merely states: "In areas of high incidence in Sub-Saharan Africa there are large numbers of women with fistulae needing surgical treatment. Precise figures are not known, but in northern Nigeria, for instance, several hospitals each have hundreds of fistula patients awaiting admission" (WHO 1989: 8). The paper never suggests that two million women currently live with the birthing injury. The authors do not claim a concrete annual incidence. Those statistics were not created until 1993.

The majority of the remaining papers citing the World Health Organization refer to a 1998 edited volume supported by the WHO (as well as Harvard School of Public Health and the World Bank) (Murray and Lopez 1998). Bangser (2006), for example, claims, "WHO estimates that more than two million girls and women currently live with fistula" (535). However, the WHO paper that Bangser cites is not an original study by the World Health Organization, rather a chapter written in this 1998 edited volume which mentions obstetric fistula only briefly, stating: "Only patchy information is available from countries where fistula are known to occur...Reports estimate that prevalence of fistulae in sub-Saharan Africa to be 1.5 to 2.0 million women, with 50,000 to 100,000 new cases occurring each year" (AbouZahr 1998: 253).

³⁹ The remaining 22% of papers split citations between other peer-reviewed articles, policy papers, or incorrect citations which led either to papers which did not exist or did not make claims about fistula prevalence or incidence.

AbouZahr (who was employed at the WHO) in turn cites a 1994 Safe Motherhood Newsletter by Dutch surgeon Kees Waaldjik, who, in turn, restates an estimation he made in a brief 1993 publication (although this time without any supporting explanation at all). Four degrees removed from a mere ballpark figure—an educated guess which is distilled from one paper to the next, strained through organizations like the WHO or UN whose reputations purify the number, reifying it to fact rather than supposition.

Indeed, in following the trail of citations, most papers eventually lead to a two-page paper written by Waaldjik and Armiya'u in 1993. In the brief article, the authors offer a very rough estimate for fistula prevalence:

From the authors' experience in Northern Nigeria, where even 700 repairs a year are not sufficient to cope with all the VVF patients presenting, the incidence rate can be calculated at 1-2 per 1,000 deliveries where the mother survives in situations where there is no easy access to a functioning obstetric unit. The annual worldwide incidence is estimated at a minimum of 50,000—100,000 new patients. As only a minority receive surgery, the prevalence is at least 500,000 patients in need of an operation; their actual number may be over two million (Waaldjik and Armiya'u 1993: 127).

Based on the authors' personal "experience," unarticulated assumptions, and rough estimations, these tentative figures almost immediately transformed into a widely consumed and repackaged truth claim. After all, it is difficult to raise awareness of an issue without any indication of its magnitude, and until 1993, none existed. So, despite the poor quality of what Andreas (2010) might call a "guesstimate," or Singer (1971) might (somewhat less generously) label a "mythical number," not only were the claims of Waaldjik and Armiya'u repeated, but often transformed. Many authors began to claim *at least* two million (Ashford 2002), between two million and three million (Mselle et al. 2011), or considered two million to be an "underestimate" (Umoiyoho et al. 2011). In some cases, 2 million women transformed into 4 million women (Bangser 2001) or an

incidence of 50,000—100,000 new cases a year transformed into 100,000—500,000 new cases a year (Browning 2004a) (a good example of what Best [2001] calls “mutant statistics”).⁴⁰

By now, the “two million” figure has become so ubiquitous that some authors have stopped providing citations at all (see Kabayambi et al. 2014; UNFPA 2002). Many other authors provide dead-end citations, referencing articles that do not even address fistula incidence or prevalence at all. For example, Milicevic et al. write, “It is estimated that there are more than 2 million women with untreated obstetric fistula” (2013: 266), citing Velez et al., who claim, “It is suspected that most of the estimated 2 million women living with fistulas are from Africa, parts of Asia, and the Arab region” (2007: S144), who in turn cite Kelly whose article makes no mention of an overall fistula prevalence rate in his two-page paper on fistula in Ethiopia. Kelly merely states, “A high prevalence has been reported from Nigeria, Chad, Sudan as well as Ethiopia. In Kano, Northern Nigeria, there are about 1,000 patients awaiting treatment at any one time” (1992: 257). An exercise like this highlights the power of one individual’s ‘educated guess’ to create and propagate an unfounded truth claim deployed to support specific agendas.⁴¹

⁴⁰ Bangser (2001) supports her claim by citing a commonly referenced publication by Murray and Lopez (1998), which only offers the standard 2,000,000/ 50,000 to 100,000 estimations. Similarly, Browning (2004a) inaccurately cites a 2002 UNFPA publication which states “More than two million women are estimated to live with the condition...In Africa alone, this means 50,000 to 100,000 new fistula patients every year” (2002: 6).

⁴¹ Much has been written about the danger of “scaling up” statistically rare events due to the likelihood of reflecting false positives. Defilippis and Hughes (2015) explains how in a phone survey conducted among 5,000 Americans on defensive gun usage, when scaled up to the entire American population, due to a host of biases, guns are thought to be used in self-defense 2.5 million times a year. However, according to media and police reports, the actual number may be closer to 1,600. Similarly, in 1994 a poll was conducted among 1,500 adult Americans asking if they had ever seen an alien spacecraft, and 150 people responded that they had. Using this same “scaling up” methodology used to calculate many statistically rare events (such as defensive gun usage or fistula incidence), approximately 20 million Americans would be thought to have seen an alien spacecraft. Defilippis explains how this exercise demonstrates how “absurd it is to scale up rare events” (Garfield 2015). Indeed, this same statistical oversight can be seen in some of the incidence and prevalence calculations for obstetric fistula. In the Malawi Demographic and Health Survey (2005), all women who delivered a live infant in the past five years were asked “After this birth, did you experience a problem such as the leakage of urine or stool from your vagina”? Or “Sometimes a woman can have a problem, usually after a difficult childbirth, such that she experiences a leakage of urine or stool from her vagina. Have you ever experienced this problem?” From these survey questions, 11,700 women, or 4.7% of women aged 15 -49 reported fistula symptoms (Johnson 2007). Although no clinical diagnostics

Cited from one paper to another, these incidence and prevalence figures have gained power not because of their merit, but because of their ubiquity. They have become a truism. In their article “Challenges in measuring obstetric fistula,” Stanton, Holtz, and Ahmed (2007) warn:

The GBD exercise estimated that there were 654,000 women with obstetric fistulas worldwide in 1990, which is one-third of the most frequently quoted number of 2 million—for which there are no supporting methods or data. We conclude that there are no convincing estimates of the global number of women living with obstetric fistulas... We discourage “author estimates” and other approaches that are not based on transparent methods and sound data, and encourage the future involvement of demographers and epidemiologists in fistula-related measurement. (2007: S8)

Despite Stanton, Holtz, and Ahmed’s unequivocal dismissal of the ubiquitous incidence and prevalence figures, the vast majority of articles published after 2007 continued to cite the prevalence of fistula as “at least two million.”⁴² In an effort to demonstrate the ways in which even made-up numbers can live long lives, circulated as truth and reproduced with little thought, Best (2001) claims, “The media repeat mutant statics; and the public accepts ... As statistics gain wide circulation, number laundering occurs. The figure becomes harder to challenge because everyone has heard them, everyone assumes the numbers must be correct. Particularly when the numbers reinforce our beliefs, prejudices, or interests” (2001: 63).

Authors have found the manipulation of data serving various agendas—artificially inflating the magnitude of crises across the globe, from sex trafficking (Feingold 2010) to

were performed, all women who reported incontinence after birth were then counted as having a fistula, and thus nearly 5% of the Malawian population was thought to have a lifetime risk for developing obstetric fistula.

⁴² Additionally, several studies have been conducted to refine incidence rates, but have not gained widespread traction, nor have the findings significantly affected widespread claims of incidence rates of 50,000—100,000 women per year. For example, Vangeenderhuysen, Prual, and Ould el Joud (2001) estimated the incidence rate of obstetric fistula in rural sub-Saharan Africa based on a prospective population-based study in six major west African cities (Abidjan, Bamako, Niamey, Nouakchott, Saint-Louis, and Ouagadougou) and one rural area in the Kaolack region of Senegal. Following 19,342 women up until the post-partum period, the authors posit a “minimum annual incidence of obstetric fistulae in rural SSA to 33,451 new cases (95% CI: 4,050—120,413)” (Vangeenderhuysen, Prual, and Ould el Joud 2001: 66). Despite a large confidence interval, a rate of 33,000 women per year is significantly lower than the often-repeated 50,000- 100,000 claim.

wartime rape in Liberia (Cohen and Hoover Green 2012). The search for data on moral panics can often be described as “the pursuit of the unknowable by the unknowing” (Feingold 2010: 56). Unfortunately, in difficult to access areas—particularly in the Global South, the bulk of numerical estimations are generated not through unbiased researchers with the methodological training and necessary access to data, rather, these numbers are often produced by non-profit organizations and invested agencies that have the most at stake, putting these numbers to work in advocacy and fundraising.

While the utilization of statistics (which are seen as cultureless, objective measurements of reality) has become an important (and arguably necessary) tool to build and maintain organizational credibility, the creation of these indicators is often an obscure process, riddled with opaque methodologies, statistical errors, and gross assumptions, frequently producing “unverifiable, and on occasion, verifiably false, information” (Cohen and Hoover Green 2012: 448). In examining the origins of “false facts,” Cohen and Hoover Green claim that, “the incentives facing a variety of actors, including activists, government officials, media sources, and academics, tend to privilege dramatic claims over those that are more rigorously verifiable” (2012: 447). While the continued dissemination of overestimations helps to achieve organizations’ short-term imperatives (to heighten awareness and raise money), in the long-term, increasingly dire claims lead to a “crisis of one-upmanship” which threatens the viability of their long-term goals (Cohen and Hoover Green 2012: 454).

Regrettably, the problem of under-scrutinized bad data far surpasses selected crises and moral panics in the Global South. In Morten Jerven’s book *Poor Numbers* (2013) on the production and usage of African economic development statistics (specifically gross domestic product, or, GDP), he examines the extent of the inaccuracy in development economic statistics

and the policy implications of poor data. “The short answer is that the numbers are poor,” Jerven warns, “This is not just a matter of technical accuracy. The arbitrariness of the quantification process produces observations with very large errors and levels of uncertainty. This numbers game has taken on a dangerously misleading air of accuracy and the resulting numbers are used to make critical decisions that allocate scarce resources. International development actors are making judgments based on erroneous statistics” (Jerven 2013: xi). Jerven concludes that most of what we know about Africa’s development is powerful “statistical fiction.” However, because numbers appear apolitical and morally neutral, statistical fiction informs politics and policy and can transcend political debate altogether.

Numbers depicting the magnitude of moral crises in the Global South are subject to little scrutiny. Weitzer argues that, “inflated claims are made about the magnitude of the problem. A key feature of many moral crusades is that the imputed scale of a problem (e.g., the number of victims) far exceeds what is warranted by the available evidence” (From Weitzer 2007: 448). In discussing the “evidence” which fuels the moral crusade against sex trafficking, Agustín (2007) argues that, “Many authors lean heavily on media reports and statistics published with little explanation of methodology or clarity about definitions” (38). “The evidence,” she continues, “is often circular, as officials cite news reports which cite officials” (ibid.). Jack Shafer argues, “Reporters have so much faith in the pure power of numbers that many will inject into a piece any ones available as long as they 1) are big; 2) come from a seemingly authoritative source; and 3) don’t contradict the point the reporter is trying to make” (Shafer 2006).

Much like GDP, MMR, sexual assault rates, or fistula incidence and prevalence, an indicator like surgical success appears on the surface to be an unproblematic quantitative capture of reality. However, although numbers appear clean reflections of truth, rendered through

standardized and transparent processes, many indicators involve a range of discretionary and often arbitrary decisions, mediated through regimes of power and the persuasion of interests. These numbers are so powerful because they are read as facts, rendering invisible the processes through which they were created, facts which are then leveraged to advance some political agendas and subvert others (Adams 2005; Hacking 1990; Kaufert and O’Neil 1990). Numbers are not simple products of the collection, organization, and computation of data—they are a distinct form of knowledge creation.

Statistics reflect not an objective truth, but rather a series of choices of what to count and how to count it often mediated by the interests of those who do the counting. Statistics often reflect systematic overcounting, undercounting, and selective counting depending on what work those numbers are positioned to do—be it galvanizing the public, justifying increased (or decreased) funding, or reflecting the success of selected interventions. Indeed, just as inflated (or at least inaccurate) numbers regarding the prevalence and incidence of fistula force global audiences to pay attention, claims of a 90% success rate convince the newly awakened audience that something can be done. The widely cited 90% success rate may not reflect actual surgical outcomes, but rather the end point in a carefully constructed narrative where surgical intervention offers a quick and efficacious solution. And just as the expectation of 90% success diminishes the credibility (and possibility for future funding) of organizations which claim 50% surgical success rates, the reliance on inflated statistics that masquerade as truth leads to the subsequent decrease in funding for organizations that opt not to espouse extreme claims. And so, the cycle cannot be easily ruptured.

* * *

As the call to prayer reverberated in the thick, dust filled evening air in Niamey, Ramatou [my research assistant] and I idled in the hot car on our way home from a long day of interviews. Both of us were lost in our thoughts; both discouraged by another round of failed surgeries. “If you had to guess, what do you think the rate of surgical success would be for women with fistula here in Niger?” I asked her. Her laugh was acerbic; then she sat quietly for a minute, thinking. “Ten percent,” she told me, her eyes becoming serious. “I don’t think it could be higher. I can count on both hands the number of women we’ve spoken with who’ve gone home dry.” (Fieldnote, October 2013)

The diversity in fistulas (and the chance that they may be successfully closed through surgery) is elided within the global media and donor fistula narrative, which simplifies fistula as a single category of injury, easily remedied through surgical intervention. However, countless studies contradict this assumption, reporting modest rates of surgical success and calls to temper inflated expectations. Quoting a fistula specialist, Brugière (2012) states that fistula is “famously difficult to treat.” He continues, “In practice, surgical reconstruction of obstetric fistulas is a complex procedure requiring properly trained surgeons. A number of surgical operations may be necessary. This kind of surgery is not routine surgery, and can only be performed in hospitals with appropriately trained specialists.” Ndiaye et al. (2009) note that, “The failure of the treatment is frequent, often giving patients the experience of multiple operations.” Still, these claims of caution do little to decrease the hopeful jubilation of the fistula narrative that situates surgical remedy as what in the early 1900s Paul Ehrlich famously called the “magic-bullet” approach to the delivery of health technologies that target one specific condition without regard to the myriad societal, political, and economic factors that create a complex context within which the condition thrives (see Biehl and Petryna 2013).

Chapter 6

Costs and Consequences of the Fistula Narrative

During my time in Niger, I came to understand that in contrast to the donor and media narrative, women with fistula are not invariably defined by their disease nor solely constituted by their pain. Most of the women I met remained entangled in complex networks of obligations and attachments that defy their supposed relegation to the margins of society. Many attempted to manage relatively normal lives for decades while living with fistula. However, the global narrative of social loss followed by surgical redemption has consequences.

In this chapter, some of the costs and consequences of the fistula metanarrative as presented in the previous two chapters are explored. I examine both the conceptual and the concrete costs of the fistula narrative, looking at its effects on how we think about Africa and intervention, and how we actually intervene into fistula. I explore how culture-blaming reinforces disempowering narratives about Africa while concomitantly failing to address systemic causes of fistula. I then examine the implications of the fistula metanarrative on fistula prevention, treatment, and rehabilitation programming, arguing that the effects of the fistula narrative are evident in long wait times at centers, reinsertion programs that fail to meet women's needs, and the disregard for women's confidentiality.

6.1 Culture-Blaming and its Backlash

The discourse surrounding fistula cannot be understood outside of the long history of colonizing and “civilizing” missions of the Global North in sub-Saharan Africa that pathologized

“African culture” and positioned Western cultural intervention as an act of goodwill. Following the standard trope of blame and salvation, Nigerien men are often situated as villains, Nigerien women are infantilized and stripped of agency, and Western actors intervene to correct African ignorance, resulting in moral salvation. These familiar narratives—like ones presented in previous chapters—are insidious. They might lead Westerners to simplistic understandings of poverty and intervention and policies and programs that may fail to address the holistic needs of women with fistula.

The Conceptual Costs of the Fistula Narrative

In donor and media literature, the causes of obstetric fistula are commonly situated as primarily socio-cultural or religious. Although authors do often note “poverty” among the long list of risks, generally, the focus remains on factors such as ignorance, abuse, neglect, local health care practices, or illiteracy. Sometimes, those most willing to openly engage in “culture blaming” are researchers from the countries about which they write, reflecting a large divide separating educated urbanites and denizens of the rural countrysides in the Global South. For example, in Nafiou et al. (2007), the Nigerien authors conclude that the woman with fistula is “*a victim of traditions dictating early marriage and delay in the search for obstetric care, even when such care is urgently needed*” (573, emphasis added). Quoted in an IRIN article on fistula in Niger, the Director of the NGO Dimol, Salamatou Traoré, explained, “Fistula is a problem that mostly affects women in rural areas where the women have no access to health services, where *ignorance and tradition prevails over common sense*” (IRIN 2007a, emphasis added). “Tradition” is situated as dangerous, sexist, and—harking back to colonial discourse—uncivilized. However, because such reprobation comes from the minds and mouths of authors who share citizenship with those about whom they speak, a certain legitimacy is conferred.

Discourses of degradation, ignorance, and dangerous culture are made (and heard) with an assumed authority.

Although vast distances between health centers, poor referral centers, and crippled health infrastructure are acknowledged, a study conducted by Meyer et al. in Niger ultimately attributes poor obstetric outcomes to cultural and religious praxis:

Because of cultural beliefs surrounding childbirth, women believe that it is unlucky to deliver outside of the family home. For this reason alone, many women are hesitant to pursue outside help. The population of Niger is 95% Muslim. Although the husband is not typically involved in the birthing of a child, if there are problems, his permission is usually necessary before moving the laboring woman to a health facility. These women also appear to have a strong sense of fate within their faith. A common reply to many of the questions that were asked in our questionnaire was that the women believed that they were in the hands of Allah and that it was not their place to question the reason that things occurred the way they did. Believing that divine intervention would protect them certainly inhibits their ability to be proactive about their healthcare. (Meyer et al. 2007: 90e3)

The fistula meta-narrative tends to focus in on parts of “African culture” deemed pathological while asserting causal relationships between forced marriage, subjugation of women, or female genital cutting and the development of fistula. These phenomena exist (and may indeed be considered harmful to women and girls) but have only indirect (if any) relationships to fistula.⁴³ Yet, in forwarding logics which rely on culture-as-culprit, structural causes of obstetric fistula are obfuscated, allowing for the mechanisms which facilitate the high incidence of fistula to continue unabated.

The role of the fistula formula seems to be to channel and focus this indignation and to propel it into the realm of intervention. I am not suggesting that this distortion constitutes some kind of willed deception of a global audience. Stories about fistula are recast and enhanced in ways that are ultimately seem to be in the interests of patients, insofar as these tales attract

⁴³ The tenuous causal relationship between fistula and early or forced marriage is dissected in chapter seven.

funding. The sensational branding of fistula ensures a steady flow of donations and heightens the global publicity of those clinical institutions that have come to patients' aid.

In an all too familiar turn of events, Africa is here, once again, relegated to the “savage slot” (Trouillot 2003), giving rise to both new and old forms of xenophobia towards “dark” Africans. Implicit in this tale and the reactions it has occasioned is a sense that a society that allows fistula to occur cannot (or will not) properly take care of its own women. The image of the young, black, female, helpless, innocent, diseased, distant subject—shunned by society and abandoned by husband and kin—invites pity, and also indignation.

By locating the problem of fistula within African culture, the fistula metanarrative obscures the systemic problems of structural violence and health access. Indeed, while the narrative situates fistula as the consequence of bad culture, oppressive patriarchy, and neglectful families, what is elided is the fact that fistula—like many other sicknesses—is deeply enmeshed in chronic poverty, geopolitical priorities, structural adjustment policies, and legacies of colonization and post-colonization, which have crippled economies and public services in the Global South.

6.2 “Resource Curse”: Examining Uranium as a Source of Poverty and Inequity

Niger is ranked last out of 187 countries on the United Nations Human Development Index (HDI Niger 2014). Behind these data demonstrating Niger's lack of development and health access is a long history of geopolitical, colonial, and post-colonial causes of poverty that enable unequal relationships, (histories rendered invisible in international development reports). It is often these historical and continued relationships—not ‘bad culture’—that engender disparities, exacerbate poverty, and inflict wounds upon the bodies of Nigerien women. To understand fistula in Niger—an injury caused by poverty, it is essential to comprehend the

country's political and economic history, particularly in relation to uranium. Although uranium has been Niger's most important and abundant natural resources, Niger has not seen many benefits from its resources, and in fact, the foreign and corporate exploitation of uranium may actually fuel the country's poverty and insecurity.

As early as 1956, in an effort to ease the tax burden to French citizens, the French government passed legislation that made African territories responsible for funding their own administrative services and infrastructure development. Soon thereafter, when negotiating the terms of decolonization, France signed a series of defense and raw materials accords with Niger (along with other newly independent African states). These treaties secured for France privileged access to strategic raw materials. For African leaders, the tradeoff gave them enhanced security through the promised military support of French troops, guaranteed markets for their raw materials, and the promise of funds for development projects.

In 1957, uranium was discovered in Niger, which is now recognized as home to the largest uranium reserves in Africa (Hecht 2012). Because uranium was not a commodity with any value until it was identified, extracted, refined, and exported, for the fledgling African nation of Niger, the development of uranium mining was an unaffordable expense—requiring massive capital investment and advanced technologies that the new state could not afford. The 1960 defense accords were thus signed, allowing France to effectively retain control over Niger's raw materials. It was not until the late 1960s and early 1970s that the Nigerien government began pushing for more control over its most valuable resource, first demanding an increase in development projects around the mines, and then attempting to influence the price of uranium. However, the Nigerien government was largely unsuccessful in setting uranium prices, as the power imbalance between France and Niger was too vast.

Much like many colonial and post-colonial relationships between former colonies and imperial powers, France leveraged its political and economic power in order to protect its privileged access to Nigerien uranium, whereby the resource could be extracted from Niger at the lowest cost, validating “a political geography in which imperial powers could continue to dominate former colonies after independence” (Hecht 2012:35).

Today, the French State-run mining company Areva continues to control most of Niger’s uranium production, exploiting two mines in northern Niger, Arlit and Akouta, mined under the Areva subsidiaries Somaïr and Cominak. Somaïr and Cominak benefit from various tax advantages including the exemption from duties, VAT, and fuel taxes. Additionally, an earlier negotiation’s provision for the reconstruction of mines lets these companies set aside 20% of their profits (which are then excluded from corporate taxation). In 2012, Areva received in 320 million euro of tax exemptions from Niger (Tran 2014). In 2010, the two subsidiaries extracted a total of 114,346 metric tons of uranium in Niger, representing an export value of 2.3 trillion CFA francs (over 3.5 billion euros). From that sum, Niger was only paid 300 billion CFA francs (approximately 459 million euros), or 13% of the exported value (OXFAM France 2013).

In December of 2013, Areva’s 10-year contract with Niger was set to expire, galvanizing Nigerien officials to attempt renegotiations with France for a better deal. Niger’s president Mahamadou Issoufou demanded that Areva increase the royalties paid to Niger from 5.5% of revenues to 12% (Tran 2014). However, although Areva pays 13% royalties for uranium extraction in Canada and 18.5% in Kazakhstan, the company refused to increase royalties in Niger (Piranty 2014).

France gets 75% of its electricity from nuclear energy, and according to Niger, one out of three light bulbs in France is powered by Nigerien uranium. Although uranium constitutes 71%

of Niger's exports, Niger's uranium deal contributes only \$140 million dollars a year, less than 6% of the gross domestic product (Piranty 2014).

Ali Idrissa, Spokesman for "Publish What You Pay," an organization that campaigns for transparency in Niger's extractive sector, argued, "While millions of homes in France are lit up by Niger's uranium, Nigerien citizens remain in the dark and in poverty. 75% of citizens live on less than \$2 a day and the average life expectancy is 53. The people of Niger have simply not benefited from their natural resources" (Publish What You Pay 2013).

Although Niger has "asked to re-equilibrate the terms of the deal between Areva and Niger," Niger's position in negotiations is severely weakened due to the paucity of any other prominent competitors due to the French saturation of Nigerien uranium markets. According to AllAfrica news:

Ultimately, many of the dynamics at play in the 60s and 70s are still prominent today as a Nigerien president pushes for a better deal of uranium prices once again... France needs Niger's uranium, while Niger needs French assistance, both military and economy. But the relationship is and always has been unequal. Despite the both parties need for each other, France has more power to set the terms for this exchange. The current negotiations—coming after years of exploitation by both French and Nigerien elites—may slightly increase Niger's income from its vast resources, but if history and the current balance of power tell us anything, it's that the Nigerien people will continue to miss out on the revenues they deserve. (Piranty 2014)

I discussed the poor state of maternal health in Niger with the head obstetrician/ gynecologist of the Emergency Department at the largest maternity hospital in Niamey. When I asked about the connection between poverty and health, he responded:

Yes, Niger is poor. There are many considerations. But, is Niger truly poor? That is the question to ask. Is Niger truly poor? Now, I think the question we have to ask is a question of management. We must speak the truth. There are people who take and mismanage our resources ... Do [Nigerien people] profit from all of our uranium? It is an essential, fundamental question... All of these companies that extract minerals, not only in Niger, but in all developing countries, if there was this responsibility [to manage the resources fairly], many things could improve.

Coined in 1993 by Richard Auty, the term “resource curse” describes the paradox of plenty, or how countries rich in natural resources are unable to translate that wealth into sustained economic prosperity, and surprisingly have lower economic growth than countries without natural resources.

When I asked the maternity hospital doctor if he believed that fistula and other maternal health problems were worse in Niger because of uranium, he responded quickly, espousing Auty’s view of the resource curse: “Oh, yes! Because, uranium makes Niger poor! Without uranium we wouldn’t have gotten to this level [of poverty].” This view is shared by many Nigeriens.

Although billions of dollars worth of uranium are mined from northern Niger each year, neither the Nigerien population as a whole, nor the adjacent communities, see these profits returned through the improvement of infrastructure such as schools, roads, or healthcare facilities. In fact, many neighboring communities, and arguably Niger as a whole, shoulder the heavy health costs of such mining operations. Yet, the fistula narrative obfuscates the structural forces that engender and exacerbate poverty, marginalize certain populations, and thus decrease access to healthcare—likely because of these alternate narrative’s complexity and political sensitivity—and instead rely on etiologies of cultural blame.

6.3 “The Leprosy of Women”: How the Fistula Narrative Creates A New Leper

New York Times columnist Nicholas Kristof described women with fistula as “the lepers of the 21st century, among the most voiceless and shunned people on earth” (Kristof 2012). The organization “Operation Fistula” refers to women with fistula as “modern-day lepers,” explaining that the condition’s “dire consequences” of social abandonment and isolation leave women segregated and isolated. Drawing parallels between fistula and leprosy, Operation

Fistula states, “The bright eyes and big smile that she once had are replaced by the pain and loneliness that only a leper can know” (Operation Fistula 2015). Dr. Rene Genadry, an international fistula surgeon who has worked with fistula in Niger since 2004, has likened fistula sufferers “almost leper-like vis-à-vis friends, family and village elders” and populations of women waiting for surgery to leper colonies (Genadry 2012:2). These parallels between women with fistula and the iconic sufferer of leprosy are used by many media outlets and NGOs to capture a specific form of social abandonment, stigma, and suffering.

Considering the degree to which donor organizations and the media have forged links between fistula and leprosy, the interest leprosy organizations have taken in fistula work is then not surprising. In the last fifty years, due to the introduction of highly effective multi-drug therapies, the prevalence of leprosy has dramatically decreased. As the non-profit sector has moved to specialize, with organizations championing single illnesses, organizations focusing exclusively on leprosy have begun to question their organizational identities and futures.

Recently, Raoul-Follereau, a foundation based in France whose mission is to aid in the fight against leprosy, has become active in fistula work in Niger. Interested in purported parallels between fistula and leprosy (and potentially in a move to keep their organization afloat as rates of leprosy have plummeted), the foundation has begun pumping money into fistula centers in Niger. I spoke with a project manager at the Niamey Raoul-Follereau office, inquiring if he believed women with fistula to be “the new lepers.” He responded:

In truth, why we say that fistula women are the new lepers is so that people understand that fistula should not be neglected. We call it the “leprosy of women” because when we say “leprosy,” people are afraid. So when we say “the leprosy of women,” people take the sickness more seriously... Fistula can have the same social consequences as leprosy. People throw you out, put you aside. If you are with your husband and you leak urine or fecal matter, your husband sends you away—even women’s own families send them away! That’s why they have to find refuge in the centers—they find others like them, their sisters. That brings them comfort. At least they know that the women have the

same sickness as them. No one will chase them away. But their families and husbands reject them.

Despite the most obvious difference between leprosy and fistula—that fistula is in no way communicable—Raoul-Follereau’s move to expand its activities to fistula, an illness that is so frequently paralleled to leprosy, has been a natural transition for many leprosy-focused organizations.

Christian Social Engineering and Leprosy as a Conduit of Evangelism

One of my four research sites, the Danja Fistula Center (located outside of the capital near the city of Maradi), is run by the secular organization the Worldwide Fistula Fund. However, Danja Fistula Center shares a campus (and some administrative power) with a missionary run health center, CSL-Danja (Centre de Santé Léprologie de Danja, or, the Danja Leprosy Health Center) run by SIM. SIM was originally established “to return to the ‘pure’ activity of preaching, converting, and establishing churches,” departing from the popularization of “service-based” missions (Cooper 2006:6). As described by historian Rosemary Fitzgerald (2001), although medical humanitarian work was initially understood as counterproductive (or at least unrelated) to the primary goal of “saving souls,” most missionary organization began to envision medical work as an entry point to evangelization. As Fitzgerald describes it:

Pain and suffering, the uncertainty of living and the threat of death were seen as transformative experiences that made the human heart open, soft and malleable. The intimate and probing nature of the medical encounter, when the patient’s capacity for mental and physical resistance was at its lowest, was held to offer matchless evangelistic opportunities. (Fitzgerald 2001:120-121)

SIM’s initial interest in leprosy (and arguably health work generally) was evangelical, not medical nor humanitarian. Medical work, health promotion, and the relief of suffering was never conceptualized as an end in and of itself, rather SIM missionaries in Niger (and throughout the Sahel) recognized the power of health centers to inculcate new ways of being, and to create

Christian converts (the production of which had proven difficult in areas like Niger that were so strongly Muslim). Through medical ministries (which were often comprised of questionable—and sometimes harmful—intervention and basic hygiene and sanitation), missionaries sought to “bring health to the ‘native’ by cleansing their bodies with soap and their minds with the Gospel” (Hardiman 2006:11). Leprosy was a particularly promising conduit to a reconceptualized mode of evangelism.

The historical ostracization and cultural marginality of individuals with leprosy made the population particularly attractive to missions across the Sahel. Additionally, as the treatment for leprosy was notoriously protracted (leprosy patients were constrained to remain at the hospital for between five to twelve years undergoing treatments initially comprised of “intramuscular injections of various oils”), the leprosarium was a promising avenue for Christian evangelism, providing a captive and vulnerable population who had nowhere else to go (Cooper 2006:305). These “colonies of sufferers” then became locations for “Christian social engineering”:

The sick were encouraged to think of themselves as having been quite literally erased by the disease, and then encouraged to adopt a new, salvatory and collective identity as ‘the lepers.’ The missionaries claimed that they were saving a socially cast-off people. In practice, leprosy patients were not always so excluded in their own societies. (Hardiman 206:33)

Missionaries depicted lepers as “wretched people in a desolate condition, but special in the eyes of Christ and thus redeemable in death through faith in Him” (Hardiman 206:34). According to historian Shobana Shankar, “Leprosy stands alone in the history of medical missions” (Shankar 2006:281). Shankar (2006) argues that because leprosy was almost categorically treated through Christian missions, Islam and Christianity were thought to have separate medical spheres and treatment for leprosy was labeled as ‘Christian.’ According to historian Barbara Cooper, although colonial governments initially attempted to curb the power of

leprosy centers to proselytize, missionaries were unambiguous about their evangelical objectives, declaring: “No evangelism, no leprosy work” (Turaki 1993:180; quoted in Cooper 2006:304).

The leprosarium in Danja, Niger opened in 1956. The lengthy stays required for leprosy treatment facilitated a Christian community life which “could become normative and individuals could be socialized into Christianity through repetition and habit” (Cooper 2006:305). Patients were required to submit to “a Gospel message” before receiving treatment, “in other words, committing to sustained treatment meant being submitted to a Christianized habitus over a relatively long period of time and finding community among participants in a distinctive belief system” (Cooper 2006:308). Because mission studies of Christian converts in the Sahel demonstrated that repeated exposure over a long period of time to “the gospel” was integral to conversion, the leprosarium was a fruitful birthplace of new Christians. And indeed, SIM’s leprosarium birthed many Christian converts—arguably due to the increased access to resources patients had through conversion to Christianity. The majority of Christian converts were former leprosy patients or their families.⁴⁴

While effective treatment for leprosy first appeared in the late 1940s, it was not until the introduction of multidrug therapy (MDT) in the early 1980s that the disease began to be diagnosed and treated successfully. Since the colonial era (and the discovery of effective treatment which has resulted in the dramatic decrease of leprosy), the leprosarium has expanded its services, offering basic medical care, a maternity (which offers pre- and post-natal care as well as supervised deliveries), and specialized services often associated (but not limited to) leprosy—such as burn care, rehabilitation, and prosthetics.

⁴⁴ The town of Danja, located 2 km from SIM’s leprosarium (now CSL-Danja and the Danja Leprosy Health Center) was settled by former leprosy patients and is now home to a large pocket of Christians, many of whom are the children and grandchildren of former leprosy patients, and now work for good wages in some capacity at the hospital or with the mission.

Making of the New Lepers

Over the years, CSL-Danja experienced difficulty remaining profitable (both financially and in terms of new converts) and the partnership with the Worldwide Fistula Fund offered not only economic incentives, but a patient population the mission believed to be similar in important ways to lepers: shunned, vulnerable, and in need of long-term care. Because stigmatized individuals were considered as “good material for proselytism” (Hardiman 2006:33), SIM’s initial interest in lepers, and recent interest in women with fistula, becomes clear—women with fistula offered the mission what lepers had sixty years prior: a population considered to be receptive to conversion.

Along with the fistula operation block and treatment ward, a hostel area with eight small houses was built, serving as longer-term housing for women with fistula. This “village” (as it is called), is a manifestation of the longer-term access that SIM may have hoped to gain to women with fistula. CSL-Danja changed its name to CSLF-Danja, or the Centre de Santé, Léprologie et Fistule (The Danja Leprosy and Fistula Health Center). On SIM Niger’s website, they highlight the importance of the long-term treatment required in leprosy care to advance evangelical objectives, claiming that the relationship between patients and staff has resulting in a “vibrant and growing Christian community.” The site continues, suggesting that women with leprosy require similar long-term care, and thus might also provide an opportunity to “glorify God, and share the gospel through our work”:

Leprosy care in particular provides a unique relationship between staff and patients due to the longer-term nature of the treatment and rehabilitation required. The fruit of these relationships has been the vibrant and growing Christian community related to Danja and its [*sic*] projects. In 2009 CSL Danja began a major partnership with Worldwide Fistula Fund, and in 2012 the obstetric fistula center was opened. The center offers specialist surgical care for women who have been injured in childbirth, and it [*sic*] growing to also include rehabilitative training. This is similar to the effort already in place for patients

who have recovered from leprosy... Our desire at Danja is to glorify God, and share the gospel through our work. This remains our purpose. (SIM Niger 2013)

In a report written by SIM Medical Advocacy Office (addressed to CSL-Danja's Hospital Director), the SIM advisors highlight the importance of the Danja Fistula Center to CSL-Danja's strategic future plan. They stress that with a 93% drop in leprosy cases since 1993, CSL-Danja must redefine their medical and ministry role and function. The letter highlights the potential importance of women with fistula, and it stresses that above all, CSL is a means to ministry first and a center of physical healing second:

With the advances in medicine, the incidence of leprosy in Niger has dropped significantly. One person wrote that since 1993 leprosy cases in Niger had dropped 93%... Given this dramatic drop, [the] question is raised as to the future role and function for CSL... The question at hand is: What medical and ministry role and function will CSL have in the future delivery of healthcare services? ... Construction of the Danja Fistula Center (DFC) on the campus of CSL, literally just a few meters from CSL, represents a major investment in the future. Physically and symbolically it represents a new direction, focused on the future. It brings a totally different clientele to the CSL campus and establishes quality maternal health programs on the campus in new buildings, with new equipment and with well-qualified medical staff to meet those needs... Included in the strategic plan would be the CSL mission, vision, values, and goals. In this document one would want to clearly define the spiritual ministry to be undertaken and how it is to be provided. To simply develop a CSL strategic plan misses the point, CSL exists as a means to ministry, reaching people with the Good News of Jesus Christ. The plan can focus on buildings and services and miss the point that CSL provides a means for the proclamation of the gospel.⁴⁵

I argue that it was necessary for SIM to accept the fistula narrative's underlying presumption of the social marginalization of young women looking for new identities, in order for the mission to accept partnering with Worldwide Fistula Fund, a secular organization that placed unwelcome restrictions on SIM's operational protocols (such as the limitation of both proselytization of patients and hiring practices restricting most employment to Christians). SIM's interest in fistula (as well as many other religious intuitions becoming active in fistula work) may primarily result from the presumption that these women are "lepers of the 21st

⁴⁵ Shared through personal email communication by CSL staff.

century” (Kristof 2012). While some organizations value the perceived similarities between leprosy and fistula, they may also be unintentionally creating or reinforcing new links through the building of fistula “colonies” or centers that isolate women and segregate them from their families and communities throughout the lengthy treatment process.⁴⁶

6.4 Concrete Consequences of the Narrative: Programming and Interventions

The dominant discourse surrounding fistula, which publicizes the risks of living with fistula, such as social marginalization or abandonment, economic instability, and social stigmatization, has some specific and direct consequences on the way fistula interventions are theorized, crafted, executed, and reviewed. The fistula narrative, and its implicit assumptions about the quality of life possible back home for women living with (and healed of) fistula appears to affect calculations as to how long women can reasonably be expected to wait for surgery in Niamey fistula centers, how long they should be kept at these centers following surgeries, and the most appropriate methods for women to be reinserted back home following their departures from these centers.

Often the long waits (discussed in chapter two) are justified by clinicians and administrators who believe that waiting on the hospital grounds is unequivocally better for a woman than returning to life as a social pariah, where her wait for social redemption would be indeterminable and without hope. Curious about the long stretches of time women waited for surgeries at centers, I would often ask administrators, clinicians, and center staff why women were kept away from home for so long. Fingers were often pointed elsewhere, and blame attributed to bureaucratic inefficiencies, corruption, or mismanagement. Yet, a more poignant

⁴⁶ Due to housing limitations and the economic burden posed by more mouths to feed, many clinics restrict patients’ families and children from staying with their loved one during the treatment process. At Danja, most women who accompany a woman with fistula are asked to return home shortly after their arrival. Infants who are still nursing are often the only exception to this rule.

social explanation emerged. Administrators and clinicians were frequently quick to add that the women did not mind because being at the center was better than the alternatives. Indeed, the fistula narrative and some health administrators glorified the “sisterhood of suffering” and posited that the centers offered women with fistula a sense of community within which they could feel more at ease around others with fistula than they did in their marital or natal communities. During my time in Niger, I heard various manifestations of this assumption from clinicians, fistula center staff, and NGO workers, including: “Women eat better here than at home,” “Women like the city life,” “Women get a break from hard work and mistreatment here at the center,” or “These women, they have nowhere else to go.” I too found some evidence of these assessments. At the centers, women often did feel less shame in leaking among other women who also leaked, less guilt about burdening their loved ones during their illnesses, and less pressure to do onerous physical labor such as farming, collecting water or firewood, or pounding millet.

However, such claims of a community of sisterhood work to displace responsibility for women’s long stays from the clinics, redirecting the accountability onto women themselves. The centers’ inability to provide rapid care to these women is reframed as a strength: the provision of a safe space, a refuge. The responsibility of centers to offer women timely access to surgical interventions is obfuscated through the fistula narrative, where long waits are no longer seen as clinical failures, but as a clinical successes wherein they reflect center’s provisioning of an oasis for women who do not wish to leave. When the global audience of the fistula narrative hears that women spend nine months or a year at a fistula center, it may not necessarily cause alarm or investigation into unethically long waits. Instead, it may be interpreted as time-intensive “holistic care” resulting in social transformation.

As discussed in chapter four, discourse surrounding fistula often focuses on one archetypical sufferer—the woman who has nothing to go home to, the woman who has nothing to lose, and nothing to risk. While these women exist, for the vast majority of fistula sufferers in my sample, this is not the case. Women with fistula have a lot to lose—their social connectedness. Forty-four percent of women in my sample had living children, 38% were married, and 36% were separated—meaning that rather than being socially unattached, for these women, treatment seeking, surgical failure, and prolonged absence can pose risks to already precarious social contexts.

6.5 Reexamining “Holistic Care”: Interventions into Psychosocial Transformation

The emphasis that many fistula advocates place on the social consequences of fistula leads them to claim that treating women surgically is not sufficient. Instead, they advocate for a “holistic” treatment that addresses the psychosocial (and often financial) repercussions of living with fistula. To complete the transformative physical and social experience offered by the center, women are often sent home with new clothing, perfume, and make-up. In many centers throughout West Africa, women who are healed of fistula are given new outfits in “dress ceremonies” on the eve of their departure from clinics. Mercy Ships, an international Christian organization that administers healthcare—particularly surgeries—through an itinerant hospital ship, frequently docks in West African ports to provide fistula surgeries. At the end of the two-week recuperation period, before women disembark, they take part in a “dress ceremony.” In a Mercy Ship promotional video, a volunteer describes the ceremony’s transformative power:

It is the most beautiful thing. Once they are dry and they have that new life, we do a dress ceremony. So we give them a new dress symbolizing a renewed sense of self. Then we give them a bible, and a mirror, and soap—just things to symbolize a renewal of themselves. They sing and they dance and they tell their stories. There isn’t a dry eye for obvious reasons. It is beautiful. (Mercy Ships 2013)

Many centers believe that the social ruptures caused by fistula cannot mend themselves as rapidly as the anatomical holes sutured together inside women's bodies. The assumptions about women's lives with fistula have led many fistula treatment centers to place a heavy focus on post-operative reinsertion training. Most centers receive funding to run often amorphous courses aimed at increasing women's standing within their communities upon return—a tool to fight fistula-stigma. Centers have crafted programs designed to give women various skills such as sewing, embroidery, knitting, weaving, husbandry, basic literacy and arithmetic (and sometimes religious education), hoping that with these skills, women who have been discarded and abandoned will have some way to provide for themselves, gain social status, and rebuild their shattered lives.

Reinsertion or reintegration programs are frequently funded to run anywhere from several weeks to several months following a woman's fistula surgery, and can cover “any experience that help improve women's lives after corrective surgery” (Lombard et al. 2015). Although programs at each center are run quite differently, women with fistula stay at centers for extended periods of time, often half-learning skills and frequently returning home still wet, but with a brand new sewing machine, supplies for an income generating activity, a new cell phone, or cash (often between \$100 to \$300 USD).

Although these courses are largely well intentioned, they are born from a particular perception of the social lives to which women with fistula will return. Rather than tacking on reinsertion programs to all fistula initiatives, the question must be asked if the value women gain from these courses outweighs the harm done by prolonging their absence from home. For some women, the answer will certainly be positive, while for others, reinsertion courses may do more harm than good. Following surgeries, some women are anxious to return home to their loving

husbands, supportive families, and young children, while others need additional support finding strategies to successfully reintegrate into their communities. Reinsertion courses thus must be individualized, responding to each woman’s specific needs and desires.



Figure 6.1: Top to bottom, left to right: A woman with fistula weaving a basket; A woman holding 75,000 fcfa (approximately \$150 USD) and a cellular phone, given as part of a reinsertion program; A sign in a Niamey fistula center: “Training in business management and leadership for women victimized by obstetric fistula.” Middle row: A woman with fistula knitting during a skill building course at the Danja fistula center; A woman beading bracelets, a skill taught to all women with fistula in Niamey centers (twelve bracelets are sold for between 100 fcfa-500 fcfa [\$0.20 USD-\$1 USD]); A woman learning to write numbers at the Danja fistula center. Bottom row: A woman learning to sew at a Niamey fistula center; Women learning to read Suras from the Quran; A woman learning embroidery at the Danja fistula center.

Not only do “reinsertion” courses retard a woman’s return home, sometimes these courses even hinder women from pursuing surgical treatment. The fistula center Dimol (which has no capacity to provide surgical interventions for women) promises monetary compensation

for women's participation in months-long training courses. Women with fistula are invited to Niamey from their villages (usually through word-of-mouth and radio advertisements) with vague promises, only to discover that they are not being offered surgery, but enrollment in a training course. Many women, like twenty-five-year-old A'i who had lived with fistula for six years, respond to a radio ad, traveling over hundreds of miles in hopes of surgical treatment. However, when A'i arrived, she found that she would not receive surgical treatment, rather a training and skill-building course:

After a failed surgery, I returned home until there was a radio message. I did not hear it myself, but my brother heard it and told me that even the transportation would be repaid. I did not know why they told me to come, but I assumed that it was for an operation. So, I came here to Dimol. But when I arrived, they said it was for a training course.

When I spoke with A'i, she had been at Dimol for over three months. She still had not been given any money and estimated that the center had only run between five and seven days of training in total since her arrival (of note, during the months I regularly visited Dimol, I had only witnessed two days of training courses). I asked A'i what she had learned during the days of training. She responded, "They told us to buy what we can to do some commerce. They told us that we can't let the goats we raise eat just anything like trash." Surprised by the apparent lack of substance in her training, I asked A'i if she thought it was worth it to come to all the way to the center. "Really, I don't know," she responded, looking frustrated, "When they called us here, I thought it was for an operation. Otherwise I would have stayed at home. I had to sell my things to raise the money for transportation here. I have nothing left and can't return home without money for the taxi."

Many women I met at Dimol had, like A'i, opted to complete their training courses and then return home (a necessary step in receiving the promised money) rather than leaving Dimol and moving to the adjacent center (CNRFO—that offered fistula surgeries, however

infrequently), risk not being selected for surgery, risk surgical failure even if they were selected, and risk returning home both wet and without the money. Perversely, Dimol recalled women for trainings who had already been “reintegrated,” encouraging them to leave their homes, their husbands, and their families for an indefinite period of time to participate in amorphous (and arguably not particularly useful) trainings.⁴⁷

Reinsertion and Confidentiality

Television stations across Niger broadcast donation ceremonies, where fabric (often emblazoned with the donor organization’s logo), sandals, soap, lotion, perfume, incense, rice, oil, and sometimes even money are given out to women with fistula. On donation days in Niamey, women with fistula are gathered together; they sit patiently while men and women dressed in suits and expensive embroidered fabrics string banners and set-up filming equipment. Eventually, a member of the organization scans the faces of women with fistula, usually choosing one Zarma and one Hausa speaker to offer her thanks to the organization on film (which would be broadcast on television stations throughout Niger). At one particular donation ceremony in Niamey, organized by the first First Lady’s organization “Guri, for a better life,”⁴⁸ a Guri administrator eyed the woman chosen to offer public thanks in Zarma. “No, we need someone younger and more beautiful,” she said to a fistula center administrator. They discussed

⁴⁷ Of note, at the time of my research, several organizations were working to craft better reinsertion programming. The reinsertion program at Danja provided an excellent model for appropriately tailored post-operative courses. Women at Danja were allowed to opt-in to the three month, highly structured training course (and were not pressured to do so nor punished if they opted out). Women who opted-out of the training course (largely due to impatience to return home) still participated in weekly hygiene and health courses as well as regular activities. Women enrolled in the training program would attend courses five days a week and learn a variety of skills, including knitting, embroidery, sewing, soap and lotion making, and basic literacy skills. Although when I left the field the Danja reinsertion program was still in its nascent stages, the center planned to provide small groups of neighboring reintegrated patients with centrally located cooperatives (equipped with the necessary tools for a small shared business, such as a sewing machine). This plan, however, required clusters of at least five reintegrated women, which due to the relatively small number of ex-patients and their geographic diversity, no clusters had been established by the time I left the field.

⁴⁸ Aissata Issoufou Mahamadou is the first wife of President Mahamadou Issoufou (the “first First Lady”). Dr. Malika Issoufou Mahamadou is the President’s second wife (the “second First Lady”).

between themselves possible women, and eventually it was decided that a young, beautiful woman with a baby would be best. Although the woman was not present, an administrator went to find her. As far as I could tell, the woman was not asked her consent to participate nor were the implications of her participation explained.

My research assistant would often come to the center, excitedly telling women that she saw them on television the night before. Women were frequently surprised to hear it. The morning after a small student-run group came and gave each woman five pieces of soap, a small bag of detergent, and half a box of powdered milk (a donation which was televised), my research assistant joked with a woman who was chosen to give public thanks that she was now a television star. The young woman was concerned. She had been hiding her fistula from everyone in her community besides her close family for two years (the ubiquity and implications of concealment will be discussed in greater depth in chapter twelve). Although there was no electricity in her village, she worried that someone would see the broadcast while in town. Other women who were featured on the broadcast (including women who were not asked to give public thanks) expressed some concern about the exposure as well. Indeed, one of the most startling implications of the fistula narrative (and its assumption that fistula is an all defining trait which cannot be concealed) is the unintentional threat it poses to women's identity as "well," disregarding her confidentiality and right to privacy while unconsciously "outing" her as a woman with fistula. Through the gift of fabrics adorned with fistula-related logos and campaigns, televised donation ceremonies, and accompaniment back home following the completion of reinsertion programs, women's confidentiality is repeatedly breached and women's efforts at concealment and self-management are continually jeopardized.

The gift of fabric (*pagne*, or *zane*) painted with fistula-related logos is a double-edged sword. Most women with fistula have limited resources. Many complain that they did not expect to be at the center for so long and thus did not bring enough clothing. Dije, a thirty-seven-year-old Hausa woman who developed her fistula following her tenth pregnancy, complained of her lack of fabric, “When I came back to [the center], I only brought one outfit because I didn’t know that I’d be here so long. Three months later I am still here and I can’t even call someone to ask them to bring me more things [because they don’t know why I am here]. When I wash my clothes, I have to run into the room to wait for them to dry because I have nothing else to wear.” Other women complained of a perpetual lack of fabric due to both their use of fabric pads and the acidity of the urine that quickly ruins all of their clothing. Maou, a fifty-year-old Hausa woman who had lived with fistula for over thirty years, complained that because of her reliance on fabric pads, she is constantly in need of more fabric, “Because of the urine, the fabric is quickly ruined. I have a difficult time getting enough fabric. Sometimes I have to use my husband’s clothing for pads. When he goes out for the day, I will use a pair of his pants or a shirt to manage the urine. Before he returns home, I will wash and dry his clothing and put them back.” As a result, when organizations offer women fabric publicizing the fistula center, an international fistula organization, or fistula related awareness campaigns, most women are not in a position to refuse. In addition, as no woman in my sample was able to read French, women may not have been aware that they were advertising fistula. These donations are problematic as women then may unknowingly advertise themselves as women with fistula once they go home.



Figure 6.2: A fistula patient wearing fistula intervention fabric. In the large circle reads “Journée Internationale de la Fistule Obstétricale 2014” (International Obstetric Fistula Day 2014). The fabric also advertises “accessible treatment with dignity for all women” along with other fistula-related phrases.

Women’s confidentiality is also placed in jeopardy when they are accompanied back home following reintegration courses. Hassia, a twenty-seven-year-old Zarma woman, was healed of fistula. However, she had returned to the fistula center due to the lasting damage done to her social life after she was “outed” in her community as having fistula by center staff. The entire time she leaked, Hassia has hidden her fistula from her community members. However, after a successful repair surgery she was accompanied back to her village by health officers, a common strategy of many fistula reinsertion programs, “[The center staff person] called a village meeting to tell everyone about fistula. She pointed to me and said that because of my fistula I shouldn’t be mocked or treated differently. I returned home, but for a month after I didn’t leave my house because I was so ashamed. I wish she had not said anything about it.” When I asked other women how they felt about being accompanied by clinical staff to back to their villages, most confessed that the prospect was worrisome and would certainly bring them problems.



Figure 6.3: from top to bottom, left to right: A woman with fistula (who was hand picked due to youth, beauty, and young child) holds donated items from a local organization while publicly giving her thanks; Bags full of donated items including branded fabric, perfume, lotion, sandals, and soap; Women with fistula sit with bags full of donated items while a local television station films them; A young woman with fistula is recorded (for a later broadcast) while giving testimony as a woman with fistula at an international fistula conference held in Niamey.

When I broached the subject of “accompaniment”⁴⁹ at an international fistula conference held in Niamey in October of 2013 (where I perhaps overly indulged in the “participation” component of participant observation), very few fistula experts understood why accompaniment might not be desired by women. In a small working group, I suggested that through the system of accompaniment, women become martyrs for the cause, used to raise community awareness of fistula, but in the process stripped of the choice to reveal (or conceal) their own health status. A middle-aged man from eastern Niger who had worked with a fistula NGO for many years was indignant (as his NGO’s specialty was reinsertion programs, culminating in accompaniment back

⁴⁹ “Accompaniment” is the word used to describe the process whereby following surgery women would be brought back home by center staff and often reintroduced to the community as a “healed woman.”

home). “Everyone in the community knows [about women’s fistulas]!” he cried, raising his hands in the air. The room seemed to split among those who believed that women could conceal their conditions and those who did not. A middle-aged woman who worked in health administration chimed in, disagreeing with the man: “I knew of a woman who had fistula for 18 years and no one knew!” One doctor from Maradi, a particularly outspoken female obstetrician/gynecologist, stood up: “For us, [accompaniment] is good. It offers us the opportunity to sensitize those who are otherwise hard to reach. But, it serves us more than the women. And the woman accepts because she cannot tell the health agents no. I am really against accompanying women back home—there are positive aspects, but the negative implications, the possibility of stigmatization, it outweighs the good.” After several hours of vigorous debate, the group decided to recommend in the presentation of our working group’s discussion to the full conference that the practice of accompaniment be discontinued. In the full session, dozens of participants wanted to discuss this recommendation, asking, “Why would you get rid of this? It is about Holistic care!” and protesting that, “This is also an opportunity for us to get the word out, and to follow up with other women who’ve been healed!”

Undoubtedly such protests come with the best of intentions. Practitioners and advocates for women’s health fight with limited resources to impact the maternal health landscape. This is not an indictment of these devoted individuals. Rather, this is a cautionary tale about how a narrative that is intended to elicit an emotional response from far-away audiences (and in the best circumstances, result in donations to the cause), can have unforeseen negative consequences.

Within what Agustín (2007) terms the “rescue industry,” a complicated relationship to “truth” exists. Hyperbole is often the means through which the currency of compassion is bought. Too often semi-fictionalized narratives supplant narrative “truths” in the service to a

greater “Truth”—the gestalt of a crisis, the intense need for intervention. Such a complicated relationship to veracity is apparent within the fistula industry, as with many moral crises which are peppered with small fictions.

* * *

A piece aired in January of 2014 on National Public Radio underscores the complicated relationship between agencies, fundraisers, journalists and truth within fistula discourse. An American photographer, Kristie McLean, purportedly found her purpose while photographing women in a fistula hospital in Ethiopia. “Typically, their husbands and their families reject them. They’re completely shunned from society,” McLean explained (Warner 2014). During her short time in Ethiopia in speaking with a man named Tsega who volunteered as a driver for the fistula hospital, McLean learned of a woman named Hijaibe whose fistula had so thoroughly destroyed her life that she had decided to hang herself from a tree. McLean recounted:

[Hijaibe’s] husband had chased her from the house and her family had rejected her and she had nowhere to go. And he [Tsega] was able to say, come down from the tree and come with us, and we have room for you in our car. And we’re going to the fistula hospital. And that was Hijaibe, she was 22. And the word Hijaibe means amazing. The name Tsega means grace. (Warner 2014)

Powerfully, “Amazing Grace” played softly in the background as McLean explained how through this story of grace and redemption, she herself found purpose. McLean returned home and told and retold this story of Amazing/Grace back in the United States, collecting donations to fund small projects for women in Ethiopia with fistula. Later, when McLean learned that Tsega did not actually talk Hijaibe down from the tree, rather a caring neighbor had, nor had Tsega met Hijaibe until months after her suicide attempt, McLean questioned if without the sensationalism of Tsega’s first story she would have been moved to act, “it’s likely we [Tsega and I] would have

shaken hands and I would have went on my way... emotion is what moves people to action” (Warner 2014).

In this short radio piece, various themes of the fistula narrative are covered: social abandonment and rejection, loss of hope, the rediscovery of hope through the gift of surgery, and post-surgical social transformation when women return home. For Hijaibe, the transformative power of the clinical encounter was not physical, but entirely social. Indeed, Hijaibe was not healed at the hospital; “Hijaibe was still living with the symptoms of her injury. Surgeons could not fix the hole in her birth canal, there was just too much scar tissue,” the reporter informs listeners (Warner 2014). A clip of Hijaibe’s sobbing is played as she remembers her life before the clinic, contrasted to her laughter and squeals of delight as she discusses her six new sheep, donated thanks to McLean.

This story leaves many questions unanswered about both Hijaibe’s life before and after her clinical encounter. If Hijaibe had been rejected due to her fistula, why would she have been welcomed back home upon return (a curious question considering her physical state remained constant)? How had six sheep changed her life and offered hoped despite her persistent leaking? If Hijaibe’s life was transformed due to McLean’s efforts, does that mean that her suffering was due more to the state of her economic situation than her physical one? Although I have never spoken to Hijaibe and cannot make too many assumptions about the social experience of illness in a country thousands of miles from where I have worked, such suggestions of transformation seem suspect.

In conservation biology a somewhat pejorative term, “charismatic megafauna,” describes a group of large animals that have widespread popular appeal such as elephants, lions, Bengal tigers, giant pandas, bald eagles, great white sharks, or gorillas. Due to the disproportionate

interest the public has in these particular animals, conservation activists often leverage these “charismatic” animals in order to achieve larger ecological goals. For example, by raising public awareness about the environmental pressures and shrinking natural habitat of their iconic animal, the giant panda, the World Wide Fund for Nature (among many other organizations) galvanize the public to donate their money, time, and political capital towards the protection of the panda—and, by extension—the entire ecosystem to which the panda belongs. The trickle-down conservation philosophy behind these efforts has been called the “umbrella effect,” where preserving one iconic animal can “save less-glamorous species that thrive in its shadow” (Marris 2013).

The girl with fistula achieves for humanitarian aid organizations, feminist activists, and concerned journalists what the charismatic animal achieves for conservationists. Women with fistula, or “superlative sufferers” as I call them, can be understood as “charismatic victims,” more captivating than the millions of women who suffer from the lack of quality maternal healthcare. But, just as within conservation biology where the trickle-down effect of the charismatic animal has been doubted (Marris 2013), the charisma of the superlative sufferer may do little to aid the maternal health landscape as a whole. Conversely, her suffering may eclipse the suffering rendered ‘ordinary’ of the millions of women in the Global South whose bodies bear witness to a health system that has failed them.

PART II:

MARRIAGE, FERTILITY, BIRTHING AND BROKEN VAGINAS

Raha's Story: The Ten-Year Pregnancy

Raha's story was difficult to follow, her narrative bounced between decades, husbands, and biomedical and supernatural understandings of the world. Frequently she would stop mid-sentence, eyeing my research assistant or pinching my biceps or belly, "You two are too thin. Are you sick? Aren't you hungry? You should eat something," she would exhort, reminding me more than a little of my own grandmother. Raha spoke quickly, jumping into her story as soon as we sat down. She was sixty, or maybe forty, possibly seventy, she told me. "We villagers don't have a good sense of time" she shrugged. Unlike the majority of women I had met at the centers, women who would fastidiously tuck hair behind hijabs, embodying a sense of piety and propriety, Raha, wore no head cover, and although she identified as a Muslim, she clung tightly to the mysteries of the spirit realm.

Raha was married at the age of 20, and had gone through twelve pregnancies, twelve deliveries or late-term miscarriages, and had mourned the deaths of all twelve babies. After seventeen years with her first husband, a maternal cousin, and only twelve small bodies buried in her yard to show for those years gone by, she left him. "People would gossip about me. Once people saw that that I was pregnant, they would begin to say that I would miscarry or birth a dead baby."

Raha believed that her inability to birth a healthy baby was due to a curse placed upon her many years before. "When I was young, I had a suitor, but I rejected him. So, he went to sorcerers and sent a curse so that I couldn't have children." Raha explained that she tried to break the curse through every means possible, but that the amulets with which the curse was

executed were hidden—she believed that one was thrown into the hole in the trunk of an old baobab tree while the other was at the bottom of a well. Her first husband spent all of his money trying to break the curse that (they believed) rendered his young wife’s womb barren.

The man was my cousin. We had the same grandparents. He did not tell me that he loved me until my marriage was already planned. I never said that I did not love him; I only said that it was too late. My father refused to break off the engagement because the bridewealth was already paid. The man was very angry; he said that I could marry, but that I would never have children. He placed a curse on me.

Raha explained that her first husband had never stopped loving her, nor had he given up on trying to win her back. “My [first] husband still loves me. He is still waiting for me! He has come more than four times to bring me back to his house, but each time I refuse. Even if I called him now, he would come to get me... But, you cannot love someone you don’t live with. So, I love the man I’m with.”

After leaving her first husband, she had successively married three other men, “My second husband was a thief, my third husband died, and now I am with my fourth husband.” With her third husband, Raha found herself again with child. But, “when the man heard that I was pregnant, he made another curse, he said that I wouldn’t ever give birth—he said that the baby would stay inside my stomach and never come out.” When Raha and her husband heard word of this new curse, her husband consoled her, explaining that after one year, they would go to the nearest hospital for a Cesarean section. “But, soon after I became pregnant, my husband died. So, I didn’t go, and the pregnancy lasted ten years.”

Throughout the pregnancy, Raha continued to see her periods, but she knew that the baby was inside of her, “I could feel her moving from one side to another, constantly shifting positions inside of my belly.” Raha looked for treatment everywhere. In the city of Maradi, she went to the home of a well-known religious healer. There were many other women there with the same

problem. “There, he gave me something to drink, a medicine, and something came out of me that night.” After Raha was given the medicine, she and the other women were told to spend the night in the courtyard of the religious leader’s home, and each woman was instructed to urinate in a special gourd. “In the morning, he came and one-by-one looked into our calabashes. He stirred the urine around with a stick, and in my calabash he saw something. It looked like a small frog. He said to me, ‘look, it is your daughter!’” Nevertheless, Raha was skeptical. She still felt the baby moving inside of her.

Finally, after many years had passed, Raha could not stand it anymore. She went to the hospital for a C-Section. “I told them that my pregnancy had lasted ten years, and they asked me so many questions. Questions and more questions!” But, eventually (after, what I imagine was a frustrating conversation between Raha and the clinicians, reflecting an irreconcilable discord between biomedical and supernatural understandings of the body), Raha was operated on.

“I believe that it was a girl; the doctor said I was lucky that I survived at all. What they took out of me could fill a large basin. The child was big, as big as your torso, but it had no forearms and no legs under the knee.” Raha crawled over to a large cement bag filled with clothing that was pushed into the corner of the room, “This is the size of what they took out of me!” she insisted. “People told me that if they hadn’t taken it out, it would have continued to grow inside of me; it would have killed me.”

Following the operation Raha believed was a C-Section, she was told to return to the hospital for a follow-up consultation. One week after her return, she had a dream. “There was a beautiful white camel above me, and it was about to fall on me. I was afraid, and I woke myself up quickly. The next day, the fistula started.” Raha consulted three Bori spirits, and was told that a bad spirit (*doguwa*) had been sent to her. She was cursed. “The *doguwa* transformed itself

into the camel in my dream. If I had not moved and woken myself up, I am sure that I would have died.” Then next morning, she went to a clinic and the midwife push on her abdomen and, “the urine, it flowed out of me!” The next week, Raha was with one of her sisters. She recalled:

My sister then had a dream and was told to ‘kill and bury,’ but it was in Zarma, and my sister didn’t understand Zarma. We went to a nurse and asked her what the words meant, and the nurse translated for us. At this point, we knew that it was about me. We knew that it wasn’t the C-Section that caused the fistula. It was caused by a curse—someone sent the bad spirit to me.

Raha adamantly continued, stressing that she did not “want anyone to accuse the doctor of doing bad work,” because, “Fistula is caused by spirits. All are due to sorcery. I am sure of it... In the days of the ancestors there were no fistula, but times are changing now. There are so many spirits among us.”

At the hospital, Raha was given a catheter and two boxes of pills. She was told to return in a month. “It didn’t help, and the urine still ran,” she recalled. Her sister, deeply skeptical of biomedicine, told her that the hospital and the pills would make her condition worse. So, Raha and her sister removed the catheter themselves, taking it (along with the pills she had been prescribed) into the bush, where they ceremoniously burned them. She went to see local healers (*boka*) and Bori practitioners, hoping to find a cure for the most recent curse that afflicted her body. But, more than 30,000 fcfa later (approximately \$60 USD), only her finances dried up, while her fistula leaked more intensely than before.

Three months before I met her, Raha was sent to the center. They put in another catheter, she told us, raising her blouse and exposing the tube she had tucked into her wrapper. Raha lifted her wrapper, following the tubing until it connected to a small black plastic bag that she had attached to the end of the tube.

I asked Raha if people gossiped about her condition. “Yes, they insult me. People say

that now that I have fistula, I can't stay with people." Raha admitted that she did not go out much anymore, restricting herself to her house. Her husband told everyone about her fistula, because he needed to recruit more women in the household to help her with her daily work. Yet, her husband was kind and loving, making for her a wooden platform to sleep on with openings that would allow the urine to flow through and fill a small hole in the ground that he had dug. Although they were no longer physically intimate, he would come to her room every morning at dawn to see how she felt. "I got fistula in his house, so he can't be too angry," she reasoned.

Raha had problems with her co-wife, who she believed was jealous of her. "Even before the fistula, when my husband would sleep in my room, in the morning, she was always angry." Because of her fistula, her husband had spent the entire previous year in the room of her co-wife, which, Raha believed, her co-wife was very happy about. "She is a difficult woman. She goes to the healer and does Bori trying to chase away other women. I am the only other wife that stayed. She doesn't want me to be healed so that our husband will always be all hers." Raha's co-wife frequently supplicated their husband to divorce her. "Now that I am here, one day he might agree. Because of the illness we have grown far apart... But, I do all of the work in the house, and every year I work with him in the field. My brother-in-law says that I work very hard, as hard as a man in the fields. So, I don't think he will divorce me."

"Women the same age as me no longer wash [see their periods], many have more than ten children. My sister-in-law was married the same time as me, now she has 14 children. But I have none. One of my sisters says that I am not a woman because I don't have even a single child," Raha stated as she stood up, signaling that the interview was over and it was finally time to eat something.

Raha's narrative leads in to a deeper examination of the expectations of normative

bodies, marital relationships, and fertility, and how tensions are negotiated when women's bodies, marriages, and fertility defy local norms. In Part II of this dissertation, themes of marriage, normative sexuality and genitals, and fertility and child bearing will be explored, particularly in their relationship to fistula.

Chapter 7

Complicating Conjugal Rupture: Marriage, Liminality, and Fistula

In this chapter, I examine the marital relationships of the 100 women with fistula in my research sample. In relation to marriage, the widespread global narrative of fistula suffering promotes two myths about women with fistulas and the communities from which they come. First, that fistula is a consequence of forced and early marriage. Second, that immediate divorce and abandonment by women's husbands are a consequence of fistula and patriarchy. I challenge these myths and suggest that this formulaic fistula narrative that is circulated by media and donor reports does not represent women with fistula in Niger. The majority of women with fistula in my research sample (74%) did not consider their marriages forced, rather women believed that they exerted agency in their choice of partners. Additionally, I found no statistical correlation between "early" marriage and "forced" marriage. Also, women who were married "early" waited significantly longer to have their first births, meaning that early marriage does not categorically mean early pregnancy.

More important to the global fistula narrative is the abandonment (or divorce) of women as a consequence of their incontinence. However, of the 100 women with fistula in my study, only 23% of women were divorced at the time of interview. Rather than demonstrating a definitive rupture in marital status, in-depth interviews with these women suggest that women's marriages were affected in unexpected ways by the onset of their fistulas. Specifically, sometimes the experience of fistula solidified marriage bonds and buttressed systems of support with a woman's husband, co-wives, kin, or community members. Other times, fistula and a

woman's quest for treatment, normalcy, and concealment, as well as other external pressures, resulted in separations and periods of conjugal uncertainty that could offer both partners an opportunity to free themselves from unwanted marriages.

Frequently women capitalized on periods of uncertainty following the development of fistulas, liberating themselves from unhappy unions, or returning to their natal homes and living for prolonged periods as "separated," experiencing neither the obligations and responsibilities nor the benefits of marriage. Following the development of their wives' fistulas, husbands behaved strategically and often did not immediately divorce their wives, tending to adopt a "wait-and-see" approach and instead diversifying assets and investing in co-wives and additional children. Often the largest marital threat to a woman with fistula did not come directly from her husband, but rather from her co-wives who may use a woman's injury to gain power over her within the household, to damage her status within her community, and to alter her relationship with their husband. Less commonly was fistula experienced as asymmetrical expressions of power, domination, and circumscribed opportunity. The diversity, dynamism, fluidity, and complexity of the local realities of marriages affected by the experience of fistula are explored in this chapter with particular attention paid to how women with fistula negotiated intimate and social relationships within the context of normative marital experiences in Niger.

Although the assertion of demographic diversity of women with fistula is uncommon in the media and donor representations, such nuances are beginning to emerge in some academic literature. For example, in a large-scale cohort study of 1,354 women with fistula in five countries, Landry et al. (2013) resolve that, "fistula affects women across all age groups, not just young women; fistula does develop among women with higher parities; not all husbands and families abandon women with fistula, and only a very small minority live alone" (15).

Specifically speaking to the experience of marital diversity, a scattering of academic literature contradicts media and donor portrayals that assume women with fistula to be “abandoned” and almost automatically divorced. Landry et al. (2013) assert that, “The common assumption that most women living with fistula are divorced or abandoned did not hold true in this study population” (11). Similarly, Weston et al. (2011) found among women with fistula in Kenya that only 11.5% of their sample had been divorced or separated, while 61.4% remained married and continued to receive social support from their husbands. In Tanzania, Mselle et al. (2011) found that a much larger percentage of their sample, “82% of women, were able to “sustain their marriages” during their study period. Similarly, in Niger, an epidemiological study conducted by Mamane with new cases of fistula in the Maradi, Zinder, and Tahoua regions found that over 90% of women with fistula were married and lived with their husbands while only 10% were divorced (Mamane 2014).⁵⁰ Mamane concludes that despite their incontinence, women with fistula continue to be accepted by their husbands.⁵¹ In a joint study conducted by UNFPA and Niger’s Ministry of Health in 2013 it was documented that of all 178 women in Niger’s six fistula treatment centers across the country, “a large majority of women are married.” Of these 178 women, 120 women (68%) remained married, while 2 (1%) were “single,” 37 (21%) were divorced, 12 (7%) were “repudiated,”⁵² and 7 (4%) were widowed (Doudou 2013). Yet, despite the overwhelming evidence demonstrating that fistula do not necessarily, and, in fact rarely, lead to marital dissolution, the accepted donor and media narratives maintain that women with fistula

⁵⁰ However, because Mamane calculated marital status as a binary: married or divorced. Because he does not record more nuanced shifts in a woman’s marital relationship such as separations, the proportion of married women may be artificially inflated.

⁵¹ “*En majorité ces femmes sont mariées et vivent avec leurs maris 90,24%. Malgré l’incontinence urinaire et ou fécale, les femmes victims de fistule vivent avec leur maris. On constate une acceptabilité des femmes par leurs maris malgré leur état.*”

⁵² They did not specify the criteria by which a woman was considered “repudiated” (*répudiée*).

are young girls forced into “child” marriages and precocious pregnancies who, following the development of their fistulas, are said to be rejected, abandoned, and divorced by their husbands.

Mirroring these low percentages of divorce, only 23 women (23% of my sample) were divorced, while the largest portion of my sample—38 women—remained married, and 36 women were in a liminal state of marital separation (Figure 7.1).⁵³ If “separated,” which I defined as women who were technically still married but both living apart from their husbands and experiencing uncertainty about their marital futures, are counted as “married,” then the percentage of women in my sample who were still married following the onset of their fistulas rises to 74%—more closely approaching the percentages represented in the studies cited above.⁵⁴

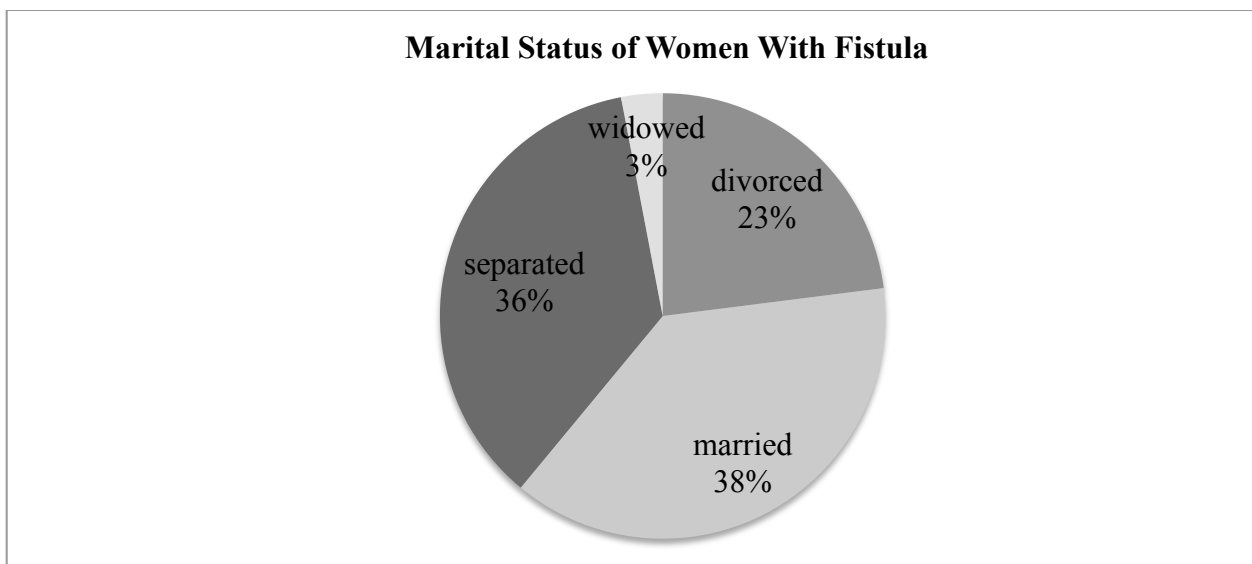


Figure 7.1: Marital status of 100 women with fistula at time of first interview. The largest portion of women (38%) remained married, while 36% were in a liminal state of marital separation, 23% were divorced, and 3% were widowed.

⁵³ Additionally, three women were widowed and none were “single.”

⁵⁴ Still, despite the relatively low rates of divorce, “married” can be as misleading of a category as “abandoned” (which is why I also include the category of “separated”). As noted by Mselle et al. (2011), “maintaining marriage or living under the same roof does not necessarily imply that there are actual marital relationships between the couple.” Indeed, just as separation or divorce do not inevitably equate with abandonment, which will be discussed below, marriage does not necessarily equate with meaningful or supportive unions. In the Nigerien context where polygamy is practiced (unlike many parts of Christian Eastern Africa, from where the bulk of fistula literature emanates), remaining “married” after a woman developed a fistula may not transmit any meaningful information about the nature of the relationship between husband and wife. Many women report that their husbands married another wife as soon as they fell ill, after they began seeking treatment, or after initial attempts at treatment seeking failed. Yet, that a husband remarries, is not in and of itself revealing as polygyny is common practice in Niger.

However, percentages alone fail to reveal the rich meanings behind dynamic marital relationships, and, importantly, the liminal state of many marital relationships affected by fistula. In this chapter, I explore the ways in which fistula affects marriages. Specifically I disentangle concepts of “early,” “child,” and “forced” marriages from understandings of fistula etiology. Then, I examine abandonment and the ambiguity of marital separations, how women capitalize on separations resulting from fistula, caretaking in the context of marital bonds, and waiting and treatment seeking as a cause of marital tension.

7.1 Defining Marital Categories

The analysis within this chapter will rely on some key marital categories that are commonly invoked by Nigerien women—such as “early,” “forced,” “family,” and “love” marriages as well as the concept of marital separation. Although there is no real consensus among my research participants or within donor literature over what constitutes “early” or “child” marriage, the age of 16 is most often used as a cut-off in international discussion of “early” and “child” marriage and thus was also used for my purposes. However, it is important to note that the average age of first marriages in Niger among women aged 25-49 is 15.7 years old (DHS 2012), making “child” marriage not a useful category for discussing marriage in Niger. According to the 2012 Demographic and Health Surveys, 30% of Nigerien women aged 25-49 had married before they reached the age of 15 (compared to 60% in my sample, see Figure 7.4) while 77% had married before the age of 18, and 88% had married before the age of 20. Although donor and media fistula narratives often use the concepts interchangeably (conflating early/child marriages and forced marriages), the *age* at marriage is independent from the *type* of marriage as women can enter forced, love, and family marriages at any age.

For the purpose of this discussion, “forced marriages” are defined as marriages that are undesired and initially resisted by the bride, often through her supplication to parents to cancel the wedding, and/or her attempts to flee from her parent’s or the groom’s house. In Hausa “forced marriage” is identified as *auren dole*, or a marriage of obligation. Twenty-five percent of the women in my sample had been in what they identified as “forced marriages” (see Figure 7.2). The reasons that women believed their parents were motivated to initiate or endorse such marriages varied, but were primarily related to creating or maintaining strong connections with the groom’s immediate family, often with blood ties to the bride’s family.

The most common type of marriage among women in my sample was “family marriage.” Fifty percent of women in the sample were in “family marriages,” often wed to a cousin. Historically, marital preference was shown for paternal first cousins, although in contemporary marriages women told me that there is more flexibility in finding a suitable match. Despite assumptions in donor literature, typically grooms are similarly aged as the brides and may be first, second, or third maternal or paternal cousins, and sometimes less direct familial connections. Family marriages were seen as the preferred marriages in Niger, particularly for first marriages as they solidified family alliances and were thought to ensure women stability within the household. It is important to note however that marital categories were not mutually exclusive as a family marriage could also be a love marriage or a forced marriage. Patrilocal residential patterns are practiced in Niger after marriage, where the bride leaves her natal home to reside in her husband’s home area. Thus, family marriages may also allow women to stay near natal homes when extended families reside nearby, providing an additional layer of protection to women engaged in familial unions.

Thirty-seven percent of women in the sample had what they conceptualized as “love marriages,” or consensual unions organized by the couple themselves (with the consent of families). These unions were marriages of choice—sometimes the couple had been in love before (“He was my boyfriend, so when he had saved enough money, he brought my parents the bridewealth,” Rabi, 26, Tuareg), and other times women described love-at-first-sight (“He was passing through my village for a baptism and he saw me in the market. He loved me when he saw me so he came to ask my parents to marry me. I liked him too, so I accepted,” Amina, 40, Zarma). Although love marriages have clear benefits for the couple—allowing both parties to enter into desired unions—they also have drawbacks. When the relationship is not moored in existing community fabrics of support and obligation (as marriages arranged by families rather than the couple themselves are) when difficulties within the relationship arise such as health problems, infidelity, or financial strain, there is less of a support system, such as a woman’s natal family, invested in keeping the relationship together. As a result, in the face of birthing injuries such as fistula, women in love marriages experienced higher rates of divorce (27%) than women in family marriages (16%) (see Figure 7.2).

Although none reached statistical significance, family marriages, which had a 16% divorce percentage, were slightly more stable than either forced marriages (28% divorce percentage) or love marriages (27% divorce percentage) (see Figure 7.2).

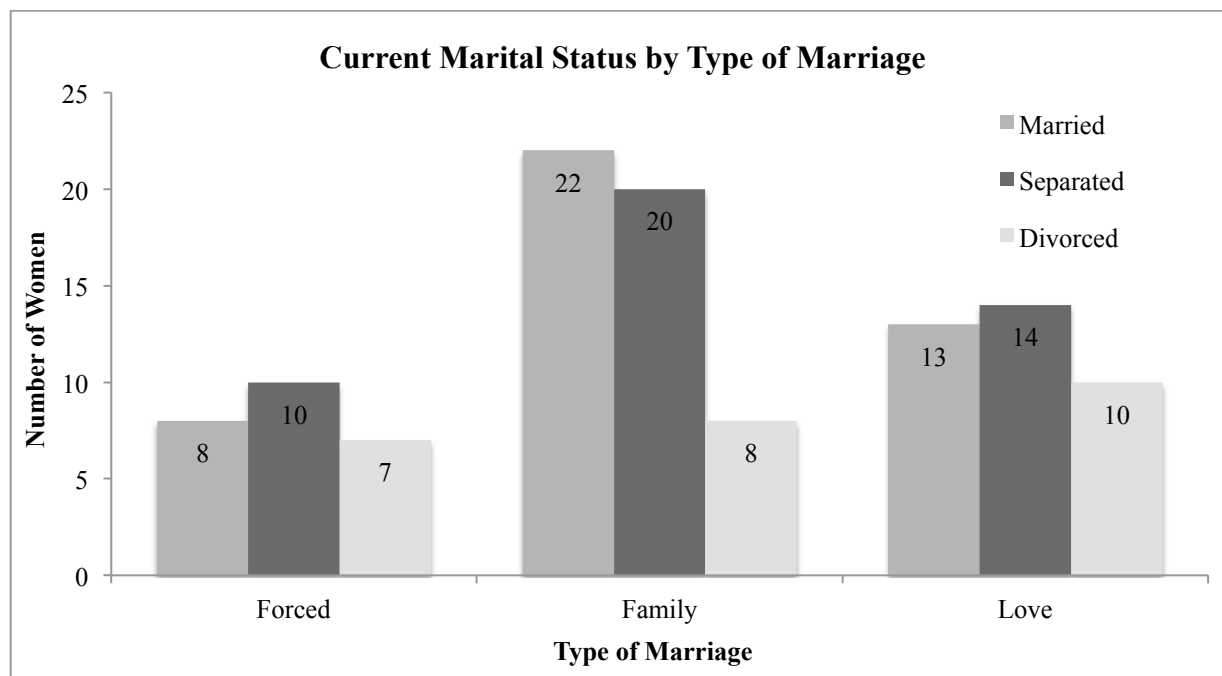


Figure 7.2: Current marital status categorized by type of marriage, including “forced,” “family,” and “love” marriages. Categories are not mutually exclusive as a love marriage can also be a family marriage, or a family marriage can also be a forced marriage. N=84. Divorce percentages are 28% for forced marriages, 16% for family marriages, and 27% for love marriages.

Finally, although the category of “separation” is not tracked in most fistula surveys, it serves a vital role for women with fistula and their husbands—providing numerous benefits and significant costs to both individuals and is essential to understanding women’s post-fistula conjugal landscapes. Thirty-six percent of women in my sample were separated, meaning that they were technically still married but both living apart from their husbands and experiencing uncertainty about their marital futures. In some cases, separations appeared to position women in temporary spaces of liminality where the woman and/or her husband were both actively negotiating the next step in their marriage (either a return to cohabitation and the attending responsibilities and benefits of marriage, or, official divorce). However, for many other couples, separations appeared to manifest as prolonged periods of liminality, extending years or decades with no communication or exchange between the couple.

7.2 Disentangling Myth #1: “Early,” “Child,” and “Forced” Marriage and Fistula

Although the concepts of “forced” and “early” or “child” marriages are distinct (one referring to a woman’s compromised choice and autonomy and the other referring to her age), donor agencies and the media (and even academics) frequently use the terms with little precision, suggesting that women in the Global South are married young, that those marriages are executed by force, and that they carry an inherent increased risk for obstetric fistula. For example, According to the World Vision campaign “Strong Women Strong World,” child unions *cause* obstetric fistula:

There is a direct correlation to areas in which child marriage is common to high numbers of obstetric fistula. The dangerous combination of girls under the ages of 16 having sex, getting pregnant and bearing a child when her body is not yet developed is one of the main reasons fistulas are prevalent. (E. Smith 2013)

In this section, I disentangle these distinct concepts of marital risk from one another (and from understandings of physical risk), ultimately suggesting that neither “forced” nor “early” (or “child”) marriages are directly associated with obstetric fistula. I argue that the utility of these concepts to the fistula narrative forwarded by media and donor agencies derives from their link to corrupted cultural practices rather than capturing inherent physiological risk.

Niger is regularly cited as having the highest rate of “early” marriage in the world. In an article about early marriage and fistula, UNICEF links early age at marriage to presumed “forced” unions: “Niger has the highest rate of forced and early marriage in the world. One out of two girls here is married before the age of 15” (Coen 2012). Based off the rich narratives of the women with whom I spoke, it appears that women do marry young and many feel powerless in the choice of their future spouses. For example, Zara, a twenty-seven-year-old Zarma woman who had lived with fistula for six years, told me of her opposition to her marriage that was arranged between her husband and father. She was married against her will when she was 11-

years-old; she claimed that she was married so early because of tradition, it was what her “fathers and their fathers did”:

I didn't want the marriage. I didn't love him, and my family didn't give me the time or choice to pick someone I wanted. I resisted and left my father's village to stay in the village of my grandmother. But, my father had conducted the religious ceremony without my consent. I was so angry. My maternal uncle gave me taxi money to run away to Ouallam [a town in the Tillabéri region of Niger], and there I met someone I loved. But, it wasn't possible to marry him because according to Islamic law, I was already married. My father was angry that I ran from my husband, but he let me stay away for a few years to mature. When he thought I was ready to live with my husband, he forced me to come back... My husband was angry that I had resisted so long. He was hard with me. Every time I made a mistake, he hit me. My co-wife didn't like me, and she didn't like that I didn't like our husband, so she would often provoke me and my husband would hit me when she and I fought.

As evidenced by Zara's narrative, there is no denying that young women in Niger do experience compromised autonomy in choosing their marital futures, and that these young women may experience social, psychological, and physical consequences when they resist such unions. But, I argue that rather than understanding marriages as “forced,” the term “constrained” marriages better captures the nuance and complexity surrounding women's conjugal choices. Just as a young girl may be limited in her choice of whom to marry and when, a divorced woman in her 20s or 30s may also feel similar constraints in a social context where remaining single is socially aberrant. Despite the importance of recognizing the ways in which Nigerien women experience limited autonomy in their ability to decide upon their conjugal futures, the evidence establishing a causal connection between “forced” marriage and fistula is scant and indirect at best.

Although “early” (or “child”) and “forced” marriage are conflated, not all “early” marriages are forced, nor are all “forced” marriages early. Often young girls initiate their own marriage plans. For instance, Salamatou, a fifty-five-year-old Fulani woman with fistula I met in Niamey, was married at 12 years of age. When I asked her if her marriage was forced, she laughed, and said, “No! If there isn't mutual love, there will be no marriage” (*babu soyayya*,

babu aurme). She married a boy she loved, a boy whom she considered her boyfriend of over a year.

Conversely, some older women are forced by their families to marry men they do not love, entering unions they do not want and often resist (in my sample, women entered “forced” marriages as late as 20 years of age). For example, Kadigya, a thirty-seven-year-old Zarma woman, was forced into an unwanted union at the age of 18-2.3 years later than the average age of marriage in Niger and 2 years later than most international cut-offs for “early” marriage. While 60% of my sample was married by the age of 15 years (constituting what many may label “early marriage”), only 26% considered their marriages “forced.”⁵⁵ Of these 26 women who considered their marriages “forced,” 18 (69%) were married at the age of 15 or younger, while only 8 (31%) were married at the age of 16 or older.⁵⁶ Despite the apparent over-representation of young women within the group considering their marriages forced, the difference in the age of marriage between the group of women who considered their marriages forced and those women who did not did not reach statistical significance ($p=0.096$).⁵⁷ Within the larger sample, there is no statistically significant dependence between the age of first marriage and if a woman

⁵⁵ Many of these ages are estimates as many women had little sense of age. For example, one woman guessed that she was six at the time of her marriage, then changed her estimate to twenty. Her clinical chart recorded her age at marriage at twelve. Most women had smaller discrepancies or simply did not know the answer. So, for my purposes, I relied on some degree of triangulation to estimate women's age at marriage. For women who did not know their age at marriage, I would typically use several data points to triangulate: (estimated current age)—(age of oldest living child + the number of years after marriage before first birth). If, however, a woman did not know her current age (many women would respond *akwai yawa*, or, “there are many years,” then I would ask women if they began menstruation before marriage or at their husband's house. If they did not begin menstruation until after their marriage, I would ask how many years she was married before she saw her first period. For these purposes, I estimated menstruation at fourteen years old.

⁵⁶ Four women were married at the age of 16, 2 women at the age of 17, 1 woman at 19, and 1 at 20.

⁵⁷ Calculated with chi-squared test for significance, comparing the age of marriage (15 or younger versus 16 or older) between women who considered their marriages forced and those who did not.

considered her marriage “forced” either ($p=0.256$).⁵⁸ Thus “early” marriage not only is not synonymous with “forced” marriage, but is not even statistically correlated. Being forced into marriage was independent from age (see Figure 7.3).

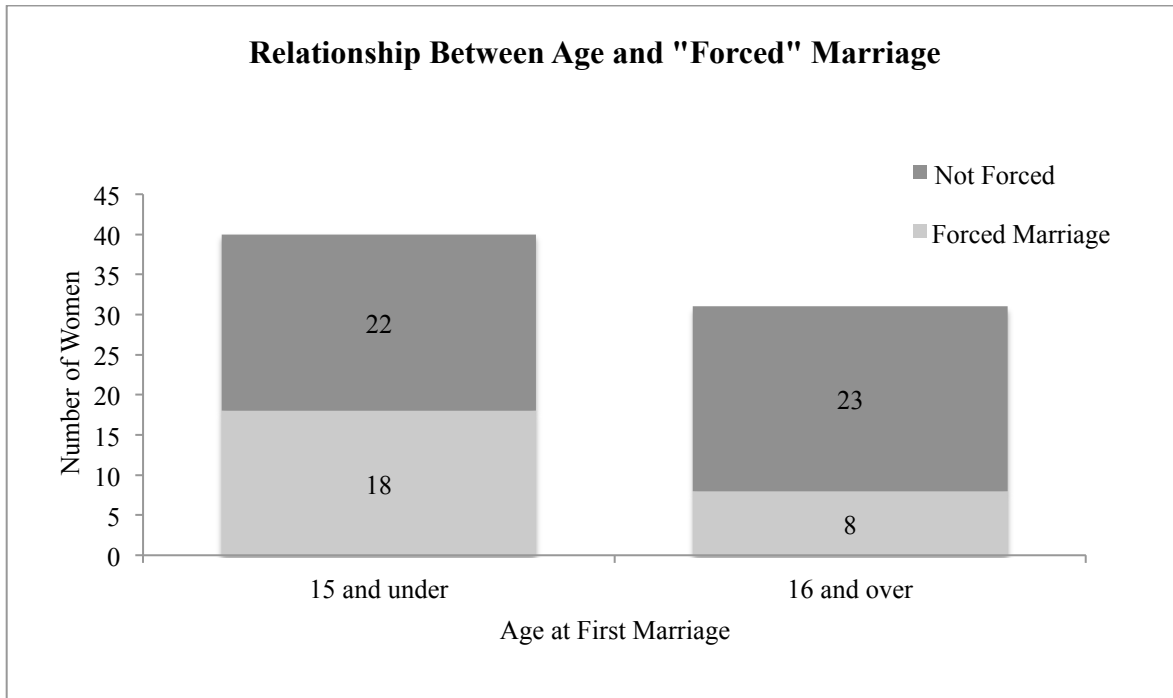


Figure 7.3: The age and marriage type of 71 women with fistula (29 women either did not explicitly qualify her marriage as “forced” or “not forced” or did not give her age at marriage and thus were not included). A total of 26 women categorized their marriages as “forced.”

While the link between “early” (or “child”) marriage and fistula may be more comprehensible than the link between “forced” marriage and fistula, that relationship too is problematic as early marriage does not necessarily mean early pregnancy.⁵⁹ While early

⁵⁸ These data were obtained through a chi-squared test for significance, comparing the age of marriage (15 or younger versus 16 or older) to marriages perceived by women as “forced.”

⁵⁹ The alleged causal connection between “early” marriage and fistula is based on the assumption that the younger a woman is at marriage, the younger she will be at the onset of sexual activity and thus the time of her first pregnancy, and the smaller and more “immature” her pelvis will be at the time of her delivery. Thus, the more likely it is that her delivery will become obstructed, resulting in obstetric fistula. The reasoning is that during pregnancy, a girl’s body will direct all additional energy away from her own physical maturation and to the development of her fetus. So, the thinking goes, a young woman whose body has not developed to maturity is at a higher risk of obstructed labor because the fetus may be too large to pass through the available space in the immature maternal pelvis (Wall 1998). It is important to note, however, that although young age at pregnancy (and thus stymied physiological development) may account for small pelvic size, other factors (not necessarily dependent on age) such as

pregnancy may indeed increase a woman's risk of developing a fistula (by inhibiting pelvic growth and thus increasing chances of obstructed labor), early marriage does not necessarily equate in early pregnancy. In my sample, there is a statistically significant relationship between the age of marriage and the length of time between marriage and first pregnancy (due primarily to delayed onset of sexual intercourse—or abstinence, rather than contraceptive use). Women in my sample who married under the age of 16 were more likely to have a longer gap between marriage and pregnancy than women who married at age 16 or older ($p=0.0005$).⁶⁰ The average amount of time between marriage and first pregnancy among the women with “early” marriages (or women who married under the age of 16) was 2.7 years while the average amount of time between marriage and first pregnancy among women who married after the age of 16 was 1.5 years. While this might be because women who are married young may not have entered reproductive maturity (marked by menarche) and are thus physiologically incapable of conceiving, ethnographic data suggests that women who are married young often experience a period of sexual abstinence following marriage.

Similarly, I found that marriage did not necessarily or immediately correlate with a sexual relationship. Within my sample I found that young women frequently continued to live with their parents following marriage until they were deemed “ready,” a subjective and individualized state typically determined by a girl's parents (and not necessarily tied to physiological indicators of maturity such as menarche or breast development). Sixty percent of women in my sample were married before the age of sixteen (and 11% were married before the

malnutrition during formative years of growth or inherited small stature may also account for reduced pelvic size. It is often cited that a risk factor for obstructed labor due to cephalo-pelvic disproportion is height measuring less than 150cm (just over 4'9"). By these criteria, measuring 4'10" at 30 years old (due neither to early pregnancy stunting my growth nor malnutrition), I could run a risk for obstructed labor.

⁶⁰ These data were obtained through a chi-squared test for significance, comparing the age of marriage (15 or younger versus 16 or older) to the amount of time following marriage before pregnancy (categorized as two years or less versus more than two years).

age of thirteen) (see Figure 7.4), yet many engaged in extended periods of post-nuptial abstinence. Rashida, a twenty-one-year-old Zarma woman with fistula who was married at the age of 14, did not become pregnant until she was almost 20. She explained, “If a young girl is married young, the husband must wait before approaching her. The elders say that if he sleeps with her too early, it can bring on problems. So [my husband] waited until I was big enough, then he approached me.” Haoua, a thirty-six-year-old Zarma woman, explained that in her village there was a tradition of grooms to migrate for work following marriage, allowing their young brides time to mature, “In my village, if a girl is young when she is married, the husband goes away for two years, then they sleep together when he returns.”⁶¹ Similarly, Salamatou, the Fulani woman quoted above who was married by choice at 12, was not sexually active until three years after her marriage and did not get pregnant until she was 16, delivering when she was 17. Habiba, a forty-nine-year-old Fulani woman, was married at 13 and lived with her mother-in-law for two years before deciding to divorce her husband. When they divorced, she and her husband had still never consummated their marriage. She explained:

It was only on the day of my marriage that I learned I would be married. Women came with marmites to cook, I asked what for and learned that I was married... But, if a girl is married before she sees her breasts, when she is still young, the husband comes every day to talk to her until she is ready. For me, we never had sex our whole marriage. He slept in another place. He gave me millet and I would prepare the meals, but if he came to me at night, I would refuse. He never forced me and I never wanted him.

For many Nigerien women, “early” marriage takes place within a context of local social conventions that control young women’s sexuality (by reserving rights to sexual access for husbands) while concomitantly protecting girls until they are thought to be “ready” for sex, pregnancy, and motherhood. This is similar to Evans-Pritchard’s (1970) observations among the

⁶¹ Still, this is not always the case and may vary by ethnic group, region, village, and even family. Hauwa, a twenty-year-old Zarma woman was sitting with Haoua during this conversation. She disagreed with Haoua, saying, “In my village, [consummating the marriage] is the same day!”

Zande, whereby a male suitor is given marriage rights to a girl-child at infancy by her parents, beginning a long process of gift exchange (predominantly unidirectional in the form of bridewealth) and privileged relationships between the two households that only leads to sexual intercourse in order to “complete” the marriage when the girl is in her late teens. Indeed, anthropological inquiry has offered an abundance of evidence that marriage is a process (as Comaroff states, “more a state of becoming than a state of being” or “the outcome of a relationship over time” [1980:171, 191]) whereby rights to a woman are conferred over a period of months (years, or even decades) rather than resulting from a discrete event. Ethnographers have demonstrated that in a multitude of settings women may be technically “married,” however may not fully burden (or in some cases, enjoy) the responsibilities, obligations, and benefits of marriage. Discussions of pre-emptive marriage, infant marriage, and sometimes child marriage often place the focus of such unions not on sexual rights, but rather rights over junior labor, future access, and household alliances.

Not only is “early” marriage not necessarily equated with “early” sexual onset, but early sexual debut is not unique to countries in the Global South. According to the Demographic and Health Surveys of 2012, the average age when female adolescents experience sexual intercourse for the first time in Niger is 15.9 (DHS 2012).⁶² Compare this to the forty percent of American girls who have had sexual intercourse by the age of 16, while 26% of American girls have had sexual intercourse by the age of 15 (Mosher, Chandra, and Jones 2002). According to the Kinsey Institute, by their late teenage years, at least 77% of adolescent American females have engaged in sexual intercourse, and 66% of all sexually experienced teens have had two or more partners (Kinsey Institute 2012). So, despite vast cultural differences mediating marriage

⁶² The age at which girls engage in their first sexual experience appears to be slowly rising, as women aged 45 to 49 reported their first sex act at the age of 15.6 while girls aged 20 to 24 reported their first sexual experience at the average age of 16.2 (DHS 2012).

practices in the United States versus Niger, the age at onset of sexual activity is not vastly different. Rather, adolescents in the U.S. are much more likely to be sexually active outside of marriage and with a reduced risk of pregnancy, presumably due to higher access to and use of contraception.

Finally, although “early” sexual onset is not unique to Niger (or countries of the Global South generally), neither is “early” pregnancy. The United States witnesses a relatively high number of teenage pregnancies each year (29.4 births for every 1,000 teen girls between the ages of 15-19 [HHS.gov]), yet obstetric fistula very rarely occurs. Deploying this same line of reasoning, Kabir et al. (2003) reason that, “Despite the occurrence of teenage pregnancies in the developed countries, obstetric fistula is a rare occurrence, therefore, it can be argued that early marriage or early pregnancy per se are not the cause of obstetric fistula, but the unsupervised deliveries” (56).

So, while women in Niger are frequently married before menarche, and sometimes have their first pregnancies not long after their first period begins, the link between “early” marriage and fistula is tenuous at best. To illustrate, while the average age of first marriage in Niger is 15.7, most studies reveal that the mean age at fistula occurrence is not until women’s *early to mid-twenties* (Landry et al. 2013; Maulet et al. 2013).⁶³ My data also support this. Of the 100 women I interviewed, I found that women developed a fistula at an average age of 23.5 ± 8.4 (avg. \pm sd), but spanning from 13 to 54 years old (refer to Figure 3.5).

An epidemiological study conducted with new cases of fistula in the Maradi, Zinder, and Tahoua regions of Niger further underscores the tenuous relationship between “early marriage” and fistula, finding that women developed a fistula an average of *six years* after marriage

⁶³ While true, averages are arguably misleading, as the distribution of ages of women with fistula in my sample is bimodal, peaking between the ages of 16-18 and again between the ages of 28-30. The mode is 17 years.

(Mamane 2014). And although women with fistula are thought to be married unrepresentatively young, I found that the average age of marriage was 15.5 ± 2.5 , spanning from 10 to 23 years (Figure 7.4), while the average age at first birth was 17.6 ± 2.4 , spanning from 13 to 27 (Figure 7.5). Considering that the average age of marriage in Niger is 15.7 (DHS 2012), and the average age at first birth is 18.6 (DHS 2012), the women with fistula in my sample are not demographically unrepresentative of Nigerien women as a whole.



Figure 7.4: The age at first marriage of 97 women with fistula. The sample average was 15.5 ± 2.5 , ranging from 10 years old to 23 years old. The national average was 15.7 years (DHS 2012).

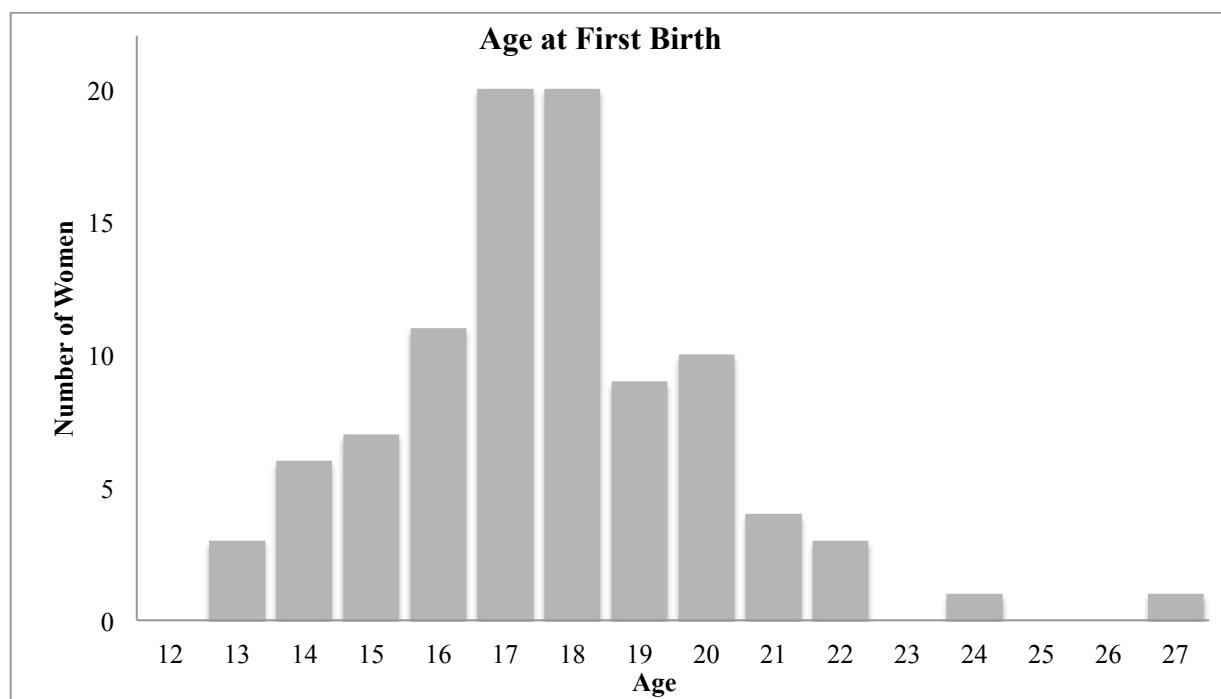


Figure 7.5: The age at first birth of 95 women with fistula. The sample average was 17.6 ± 2.4 , ranging from 13 to 27 years old. The national average was 18.6 years (DHS 2012).

7.3 Myth #2: Abandonment, Liminality, and Marital Separations

Despite the diversity in experience of women with fistula, media and donor narratives as well as some academic literature depict a situation in which her husband becomes disgusted by her odor and ashamed by her condition, and hence abandons her. And indeed, some women do experience an immediate marital rupture that may exemplify the fistula narrative’s framing of “abandonment.” For example, Adama, a twenty-two-year-old Hausa woman who had been living with fistula for two years, explained how since she developed a fistula, she had not seen nor spoken to her husband:

When I was in the fifth month of my second pregnancy, my husband went to find work in [a town on the border with Nigeria]. He left and he didn’t come back even when I gave birth. Now it has been three years and I haven’t seen him. A friend of his told him that I got fistula, so he never came back... I hear that now he is married and has a child... This year he sent me divorce papers. It is because of my fistula that he never came back. He never once called me. He never even gave me 5 fcfa [\$0.01 USD].

Still, even for women like Adama, the definitive term “abandonment” often fails to reflect the ambiguity and diversity of women’s conjugal futures following a fistula. While some husbands do divorce their wives directly following the development of fistula, many more accept separations, often waiting to decide on any definitive course of action until after their wives have explored various treatment options. Instead of abandonment, the notion of liminality better captures the experience of many women I interviewed who often were not living with their husbands. Investigating the ambiguity surrounding a woman’s post-fistula conjugal future is important not only because it is an integral component of the fistula experience, but because categories such as “abandonment” are given so much analytical power by outside observers in demonstrating the degree of a woman’s mistreatment.

Most women in Niger deliver and recuperate for forty days post-birth at their parents’ and not their marital home, a custom that holds particularly true for younger women. Rather than a marker of marital friction, a woman’s departure from her matrimonial home for her delivery and postpartum recovery is a widely practiced custom that allows a woman respite from onerous domestic and sexual duties while in the late stages of pregnancy. Additionally, the practice allows women the time and space to follow postpartum healing and cleansing rituals while adhering to a strict minimum requirement of forty days postpartum abstinence. Particularly common in first, second, and third births when women are young mothers, the practice is known among the Hausa as “*shan kunu*” (“drink porridge”) and allows a young bride to return to her natal home to give birth to her child and remain there for many months to rest and eat well (Cooper 2006). Sometimes *shan kunu* far exceeds the minimum forty days and may extend until the child is weaned at about two years of age (Cooper 2006). In cases of birthing injuries, reticent to return to their marital homes and attendant domestic responsibilities until they have

convalesced, women frequently remain at their parents' homes, extending normal postpartum absences. These postpartum absences up to several months are not unusual, but when a woman's incontinence does not eventually subside, and her body does not return to "normal," she must then negotiate the meanings behind a prolonged absence from her husband, both within her individual relationship with him, and within a larger social network of invested stakeholders such as her co-wife, in-laws, her own family members, and curious neighbors or community members who may have something to gain or lose in her absence.

Husbands (and sometimes wives, as demonstrated below) capitalize on this period of uncertainty, behaving strategically and often not immediately divorcing their wives when they develop a birthing injury. Husbands have already invested a great deal in their marriages and thus tend to adopt a "wait-and-see" approach when their wives develop a fistula. Frequently, they decline to invest further in the relationship, often opting not to care for their wives financially during this period and disinvesting in other respects as well—and, to continue the economics metaphor—diversifying their investments, potentially searching for an additional wife—a strategy enabled through the common practice of polygamy in Niger. Rabi, a twenty-five-year-old Zarma woman who had lived with fistula for three years and undergone four previous surgeries, explained to me her uncertainty regarding her marital status:

I don't know if we are still married. It has been three years since I have been at his house. He comes to visit me at my parent's house, but he does not give me money. When he comes to visit, he asks me about my health; he asks if I am better. He says that if the sickness is finished, I should go back to his home, but if not, he says I should stay with my parents... My mother-in-law told him that he should remarry because when she saw the state I was in, she knew that I would never be the same. She said that there would always be urine. Now, if I said that I did not want him anymore, it would not be a problem for him because he has already remarried. He has a young son... If I am healed, and he continues to visit me, I will go back to him. But if he stops visiting, then I won't go back.

As Rabi's situation illuminates, both husband and wife are forced to reexamine their marital configuration after the onset of fistula, constantly recalculating the costs versus benefits of possible futures following the liminal state of separation. In many cases, the transformation post-fistula that takes place in a relationship is complicated, ever dynamic, and largely influenced by factors other than the injury.

Rather than signifying "abandonment," during this liminal phase, particularly before and during the treatment period, it may be unclear to both wife and husband the state of their marriage. Often, it is not until a woman undergoes failed surgeries, or during an extended treatment period, that a husband may choose to divorce his wife.⁶⁴ The period of ambiguous separation, where there is a "marriage cord" (*igiyar arme*), but often little substance to the relationship, inhibits women from marrying elsewhere, but allows men to disinvest financially, and often take other wives, minimizing any consequence to husbands of 'waiting' for their wives to receive treatment.

This period of liminality can also serve to benefit women. Although some women do push for official divorce so that they may remarry,⁶⁵ many women with fistula prefer to live within the boundaries of a technical marriage even if that union is without substance or material benefit. While these liminal marriages do not have the same financial, emotional, sexual, or social benefits of a substantive marriage, nor do they have the attendant responsibilities or obligations. Separations thus allow women to live within the socially normative role of married adult (rather than slipping into the socially problematic role of an unmarried woman) and the

⁶⁴ In examining fistula in Niger and Mali, Maulet et al. (2013) remark upon a similar observation, observing that fistula led to marital rupture at three notable periods: "immediately after incontinence diagnosis, later when care seeking took longer than expected, and finally when the irreversibility of incontinence was diagnosed or feared" (527).

⁶⁵ Women are typically granted these divorces by religious leaders or state authorities when their husbands refuse to grant them.

space to care for themselves and manage their incontinence away from the close quarters, and often the accompanying judgment, insults, gossip, and/or mockery, of their co-wives. Typically, women live with relative freedom and independence within their natal homes, allowing women the time to dedicate towards the onerous quotidian work of fistula self-care or to pursue medical treatment outside of their communities while retaining hope for their future return to their marital homes once healed.

7.4 Women Capitalizing on Marital Separations

Following periods of separation, divorce is often a quiet process rather than a discrete event. A woman may stay at her parents' home after labor, as she might have otherwise, but the husband never gives her money, never visits, and never asks her to come back home. The divorce is often divorce by omission—omission of money, care, conjugal visits, or any substance that makes a marital relationship. Months or years after the labor that caused fistula, a representative of the husband's family may show up with divorce papers, or bring the news that the groom had performed a religious divorce.

Still, many women make the decision to leave their husband's home of their own volition; blaming him for their injury, angry at his lack of care, or unhappy with the marriage in the first place, women often capitalize on a period of conjugal uncertainty to liberate themselves from an unwanted union. Indeed, fistula often serves as a socially sanctioned point of rupture for both husbands and wives, allowing either party to gracefully (and sometimes passively) remove themselves from an unhappy marriage. I found that the couples that divorced immediately after the woman developed a fistula were often unhappy to begin with.

Maimouna, a thirty-two-year-old Zarma woman, developed a fistula just a few months prior. Her legs were atrophied and thin, as neither leg had worked since her labor six months

before due to nerve damage. She explained that she had not spoken with her husband since she got fistula:

I am at my parent's house, but I am not divorced. My husband hasn't come to visit; he hasn't sent money. He didn't come to visit me when he learned that the child was stillborn. He didn't even come to give his condolences...He was angry with me because I had told him that I didn't want to stay with him even before the birth. When I married him, he already had a wife, but he chased away his first wife and soon after, he married another woman. But his first wife came back, so then there were three of us. No; it was just too many women! I told him I wanted a divorce, even if he didn't give me my papers... People gossip about me. Because I refused to stay, because I left him, that's why. I've been with him for six years, and I leave him often. Before, I had always gone back. This time though, I don't think he will make me go back to him. I think now it is done.

Even before the onset of her fistula, Maimouna's relationship with her husband was filled with tumult. Although it is not clear what is best for Maimouna, or what she actually desires, the development of her fistula may have helped to remove her from a marriage she "often" tried to leave.

Sa'a, a twenty-seven-year-old woman who was married against her will at 11 years old, explained how fistula ended her marriage: "When I returned from the hospital, my husband came to visit me. He told my uncle that if I ever healed, I could find another husband. He said that he didn't want me anymore. Even my mother-in-law came to tell me." I asked how the divorce made her feel, and she responded: "So happy I even laughed! This is what I had already wanted. I was joyous." For Sa'a, her fistula allowed her to escape a marriage that despite her best efforts had been inescapable in her youth.

Many women, like thirty-seven-year-old Zina, who had lived with fistula for twenty years, have complex marital histories that defy simple categorization:

When I came back from the hospital [following the labor which resulted in fistula], my husband came to visit me at my mother's house. He gave me 2,000 fcfa [approximately \$4 USD]. That's all—then and after. When I went to [city in the north of Niger] to look

for treatment, he took two other wives... When I came back from there, I preferred to stay my parent's house, but he came and got me and told me to come home.

One of his wives was so angry at him because of this—she protested that he would bring a sick woman to the household. She told him to divorce me. He said he would not divorce me and chased her away instead... I asked him why he chased away his wife because of me, and he told me that he loved me... I stayed with him many years and was pregnant four more times, although only one child survived... He didn't mind that I leaked.

When my daughter was two years old, I was happy with my husband but my co-wife was very jealous. She saw that even though I was sick, he loved me more than he loved her. So, she went to get medicine from the local healer (*boka*). My husband then spent six days without coming to my room, not during the day or the night.

I told my husband's sister, and she believed that my co-wife was to blame. She believed that my co-wife commissioned a medicine to make my husband leave me. My sister-in-law advised me to be patient, but she said that if I couldn't be patient, I should return to my parent's house—if my husband still loved me, he would come to get me.

I went to my parent's home, and I spent a year there waiting, but he never came to get me. Finally, three years later, he came and asked me to come back. I said no, and came [to the fistula center] instead. He refused to give me my divorce papers. I had to go to the police and demand them. Now I am divorced.

When authors note that women with fistula are frequently “abandoned,” there is rarely any specification of what abandonment means, what it looks like, or how it is measured.⁶⁶ Would a woman like Zina qualify as abandoned—a woman whose husband loved her despite her incontinence, lived with her for many years, and protected her from mistreatment from her co-wives, because he left her for three years? Does abandonment simply mean a woman is divorced? Or that she is separated? That she is still married, but mistreated? Is she still considered abandoned even if she fought for her divorce? The category of “abandonment” compels diverse marital configurations and their meanings to be understood through the singular lens of victimization. The complex ways in which marriages are affected by the development of a fistula, and the liminality many women with fistula experience (frequently expressed as an

⁶⁶ An exception is Maulet et al. (2013) who in an 18-month cohort study of women with fistula in Mali and Niger define marital abandon as “women without any sign of their husband during 1 year.” However, even as defined here, it isn't clear why one year was thought to denote “abandonment”—if these categories emanated from women themselves or if women's conjugal narratives were categorized by researchers. The lack of contact for one year could just as easily reflect tortuous health-seeking episodes, whereby a woman moves from hospital to hospital seeking care, waiting long periods of time, and going without contact due the lack of cell phone coverage (or cell phones) back home.

uncertainty regarding their own marital present or future) are obfuscated by reductionist typologies that transmit very little texture to the experiences of women affected by fistula. In many ways Zina's story is typical of the stories of so many women with fistula across Niger in its fluidity and complexity, in the overlapping role of love, prolonged negotiation of illness, and tumult and tension due only peripherally to fistula but more directly to co-wives, jealousy and the allocation of resources and romantic attention.

7.5 Polygyny and Co-wives

The way in which fistula affects marriage in Niger cannot be understood outside of the context of polygyny. Co-wives can often offer a stay on decision-making post-fistula, buying time for women with fistula to strategize on their futures and care for their bodies while husbands invest in a second relationship and family. Co-wives can, at least temporarily, mitigate the pressure placed on couples to engage in regular sexual intercourse and to reproduce, and in doing so, allow for women with fistula to avoid unwanted divorce. However, in the context of illness, co-wives can also prove harmful to women with fistula, using a woman's injury to gain power over her within the household, to damage her status within her community, and to alter her relationship with their husband. Because a co-wife has the power both to protect and to harm a woman's relationship with her husband following the development of her fistula, the existence of and relationships to women with fistula's co-wives prove complex, fluid, fraught with anxiety, and predictive of marital outcomes.

Among the 71 women in my sample who were married, separated, or widowed (excluding the 23 women who were divorced and 6 other women who did not know how many co-wives they had due to prolonged absence), only 27 women (38%) had no co-wives, while the remaining 44 women (62%) lived in polygynous households (34 women, 48%, had one co-wife,

8 women, 11%, had two co-wives, and 2 women, 3%, had three co-wives—see Figure 7.6). As only 36% of women in Niger are in polygynous unions, compared to 62% of this sample, these data suggest that fistula significantly increases the chances of a husband seeking additional wives when his wife develops a fistula.

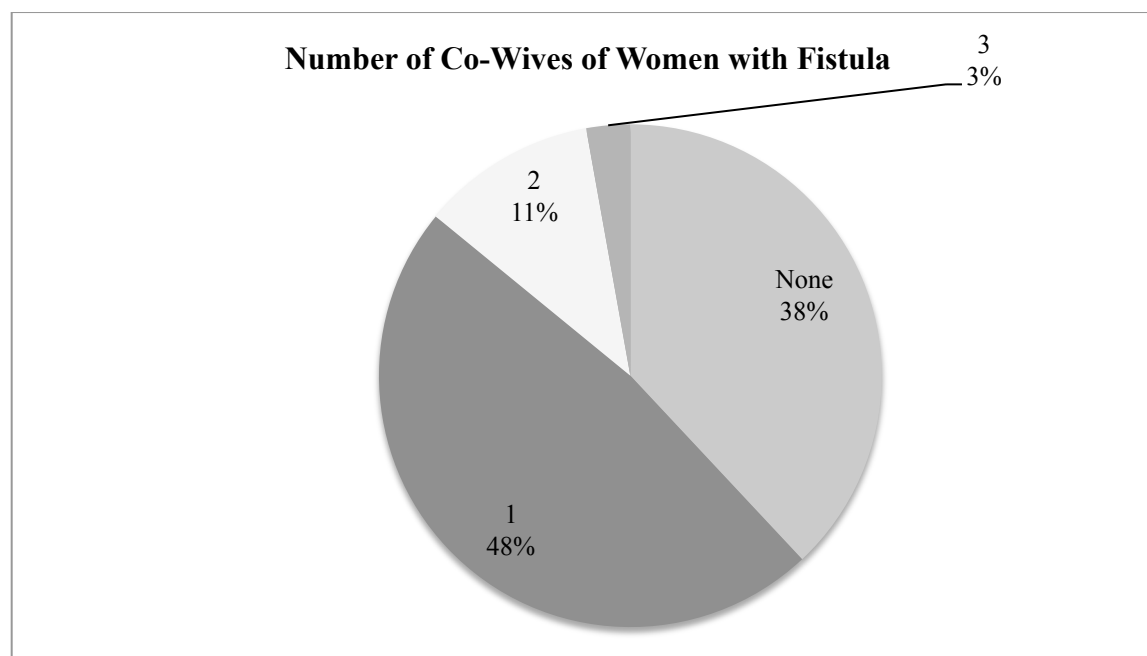


Figure 7.6: Number of co-wives among married, separated, and widowed women with fistula. N=71 women, 29 women were not included—23 of whom were divorced and the remaining 6 women did not know how many co-wives they had due to prolonged absence from home.

Similarly, in examining fistula in Niger and Mali, Maulet et al. (2013) note that a common change in marital status was the addition of a co-wife—22 of 76 of the participants who remained married after their fistula had to accept another co-wife into their households.

Most women in Niger will live with a co-wife at some point in her life. Within sub-Saharan Africa, polygyny is most prevalent in West Africa,⁶⁷ predating Islam, and is associated with patrilineal, patrilocal, gerontocratic, pronatalist agrarian societies where women's access to

⁶⁷ Some scholars believe the higher rates of polygyny in West Africa in relation to the rest of sub-Saharan Africa can be attributed to the African slave trade, whereby more male slaves were exported in the trans-Atlantic slave trade from Western Africa while more females were exported as slaves from the Indian Ocean from East Africa. Claims have been made that the resultant prolonged period of abnormal sex ratios in West Africa encouraged polygyny (see Dalton and Leung 2011).

land, inheritance, support from natal kin, and formalized power are typically limited (Bove and Valeggia 2009; Goody 1973; Murdock 1967). In Niger, only 20% of women aged 15-19 are in polygynous unions, steadily increasing to 47% once women are between 45-49 years old (DHS 2012). Although 30.4% of Nigerien women have one co-wife,⁶⁸ only 5.7% of women have more than one co-wife (due to the increased cost of living and general scarcity of resources few men can afford more than two wives).⁶⁹

Despite the near ubiquity of polygyny in Niger, the vast majority of women admit that living with a co-wife (even when one is well) is difficult and requires patience, humility, and one's control over jealousy. Describing a paradigm of "co-operative conflict," Bove and Valeggia (2009) suggest that women in polygynous households adopt both cooperative and competitive strategies in order to negotiate their relative status within their households: "Polygyny structures social relationships within the household by requiring cooperation among co-wives in productive (domestic, agricultural) and reproductive (conjugal, childrearing) arenas, all while placing them under the authority of a husband for whose attention and parental investment co-wives are in direct competition" (22). A woman's attitude towards her co-wife or wives, and thus the intensity of a competitive versus cooperative approach, is mediated by myriad structural, socioeconomic, and cultural factors, including sexual jealousy, reproductive competition, emotional closeness, closeness in age and parity, abundance of resources, and proximity to natal households, to name a few.

⁶⁸ In total, 36.3% of all Nigerien women are in polygynous unions (DHS 2012).

⁶⁹ Older women (between the ages of 45-49) and the most affluent women are most likely to have more than one co-wife (11% for both), in the former case due to a woman's decreased reproductive capabilities (and thus sexual responsibilities to her husband who may then opt to take a younger wife if he can afford it) and in the latter case due to the considerable expense associated with marriage and with supporting another wife and her children (DHS 2012).

There are many perceived benefits to polygyny for Nigerian women, primarily for older women whose social position is already secured (generally through the successful bearing and raising of multiple children, particularly boy children) and who may have an eased burden of domestic chores and sexual responsibilities at home when a younger co-wife joins the household. First wives often encourage their husbands to take a second wife and typically enjoy social respect and managerial power over her junior co-wives. However, a first wife often must tolerate her husband displaying preferential treatment to his more junior wives who are thought to receive sexual, as well as material, favoritism. Although the Quran explicitly allows polygyny under the condition that husbands are able to treat all of his wives equally, never demonstrating favoritism, women readily admit that husbands often fail to do so. In Hausa, the words *bora* and *mowa* are frequently used, referring to the least favored wife and the favorite wife respectively (commonly employed in the proverb: *Ba a mowa sai da bora*, or, “one does not have a favorite wife unless he has a least favorite”). Because first marriages are commonly political, building alliances between or within families, many consider first marriages as unions of obligation and familial alliances while second marriages are considered unions of love (as a result, many Nigerian men and women agree that second wives are often “more loved” than first wives). According to Rakiya, a thirty-year-old Hausa woman, “Some [women] want to be the second wife because she tends to be spoiled by the husband. She tends to be better loved by the husband. But, the difference is that the first wife doesn’t do as much work. In my village it is always the second wife that cooks.”

However, if a husband is able to treat his wives with relative equity, then co-wives may offer one another emotional and domestic support. In her research among the Bedouin, Lila Abu-Lughod (1993) demonstrates how in the absence of intense competition over resources, co-

wives often formed close bonds, sharing experiences of childbearing and childrearing and quotidian household chores. Similarly, Madhavan (2002) suggests that in Mali, older women whose social position had already been secured through the marriage of their sons tended to compete less with co-wives, happily allowing their co-wives to take on more marital (often sexual) responsibility. Ultimately, Madhavan (2002:82) suggests that, “There is little doubt that jealousy exists, albeit in varying degrees, in most co-wife relationships, but it does not necessarily preclude collaboration.” Yet, in the absence of good health, the delicate balance between collaborative and competitive relationships between co-wives is often upset.

Although a husband taking a second, third, or fourth wife is fairly normative, often the illness of a first wife may be a precipitating factor that pushes a man to find another wife more quickly than he might have otherwise. Indeed, when women fall ill and can no longer manage domestic (or sexual) responsibilities either due to the illness itself or her resultant absence as she seeks care, men often find it necessary to take another wife in order to maintain a balanced and well-functioning household and to ensure the continued fertility of his family line. During periods of illness (as is also the case during periods of menstruation, postpartum taboo, late pregnancy, and absence), a woman’s co-wife or wives are expected to assume many of her co-wife’s domestic and conjugal duties, including childcare, food preparation, domestic chores, and sexual responsibilities (Madhavan 2002). Although many women may experience this positively, feeling unburdened from onerous household duties, others experience this as a usurpation of power, status, and security within their households. Bove and Valeggia (2009) suggest that when a woman falls ill within a polygynous household, the competition experienced between her co-wives might exacerbate her ill health: “The mere contrast between one’s illness and a co-wife’s good health might induce anxiety and distress in a polygynous women who is

sick. Co-wives may also affect the care that women receive, either through support offered (e.g., by the ‘social security’ junior wife) or withheld, or by interfering with the patient’s relationship with her husband” (26).

Mariama, a thirty-five-year-old Hausa woman, explained to me how even during her illness her co-wife “showed that there was love between us”: “Since I fell ill, my co-wife has taken care of me, our husband, and my children. She braids my children’s hair, pounds my millet. Really, she does everything for me. She has never used my fistula against me.” Yet, while some women did experience continued support from their co-wives in the face of illness, many did not. Such mutually supportive relationships may be the exception rather than the rule.

The tensions among co-wives that accompany illness may be exacerbated when a woman’s reproductive health is questioned. Various studies indicate that infertility or low fertility more negatively affects women in polygynous relationships than women in monogamous marriages. In a study in Nigeria of women with infertility, polygynous unions were associated with greater psychopathology (Aghanwa, Dare, and Ogunniyi 1999). In a study in Ghana, the presence of a co-wife exacerbated the distress women experienced when confronted with fertility problems (Donkor and Sandall 2007). Hollos et al. (2009) suggest that among women in Nigeria, infertility in a polygynous union is the cause of many marital problems as co-wives “frequently disrespect her and can make her life very unpleasant,” resulting in women “invariably leav[ing] the marriage” (2064). Because a woman’s ability to negotiate delicate social relationships within her household is vital to her (and her children’s) emotional and economic wellbeing, when a condition with fertility implications strikes, household equanimity may be severely disrupted.

Avoiding household tensions is thought to require a prudent husband who is equitable with his wives and just, and sufficient household resources to diminish the chances of resentment between wives and silent warfare over resource allocation. However, in the face of fistula, an illness that may result in substantial economic loss, long periods of absence, and volitional abstinence due to a woman's incontinence, such equitable distributions of time, money, sexual interest, and emotional closeness are rare, often resulting in increased tensions between co-wives and a woman with fistula and her husband. Amina, a forty-five-year-old Fulani woman who had lived with fistula for ten years, developed a fistula following her seventh pregnancy. Although Amina was married, she had not lived with her husband for nine years:

Our fathers are brothers. We grew up together in my grandmother's house. Before this sickness, we didn't have any problems. But my husband married two women after me. He married the first after my labor when I couldn't walk, and the second when I started coming to hospitals to find treatment. For me, the problem is that he remarried before I even finished my forty days.⁷⁰ People had told him that if a woman gets this sickness, she would not get better. His friends told him about [fistula]. They explained that if a woman had this sickness, she couldn't stay with her husband. So he listened and he remarried...

Now I am at my parent's house. But when I go home from the hospital, he will come and visit me and wish me welcome. Since I got sick, I have only spent one year at his house, but the last nine have been at my parent's house. If my children want to see me, they can come and visit... My husband wanted me to go back, but I refused. I don't like being with the co-wives. I never know when I will leak, and I don't want them or their children to see me wet... My husband's second wife never insulted me directly, but if her daughter would come into my room, her mother would yell at her and send her away so that I didn't dirty her. I told my husband, but he didn't believe me. He didn't believe that she would say that...

Even if I go back one day, I won't stay with his other wives. My oldest son will build me a hut and I will stay with him. If it wasn't because of this sickness of urine, when you [go through menopause] and you are lucky enough to have an older son, he will take care of you until you die.

When I asked Amina if she was angry that her husband remarried so quickly, she said she was not, "He informed me that he wanted to remarry and I agreed. If he had guests, who would serve

⁷⁰ In Niger, forty days following labor are often reserved ceremonial post-partum practices to allow a woman to regain her strength and health.

them? Who would take care of him?” Although Amina recognized the importance of her husband remarrying in order to maintain his, and thus her and her children’s, social status within the community, her tumultuous relationships with her co-wives, but not her husband, prevented her from returning to her marital home. So, while her co-wives proved instrumental in protecting the integrity of Amina’s household—caring for her husband and children while she was ill and searching for treatment at hospitals—her co-wives presence and inimical relationship to her also hindered her ability to live with her husband, despite his desire for her to do so.

Salamatou, a forty-seven-year-old Hausa woman who had lived with fistula for 30 years, had undergone nine pregnancies and nine labors, but was left with no living children—not uncommon among women with fistula (high infertility and infant mortality rates will be discussed further in Chapter 11). Seven of Salamatou’s children were stillborn, one child died after three days, and her twins died within a day of their births. She attributed her marital problems to both her diminished power in the household due to her lack of children, but also to the tension between her and her co-wife:

For twenty-nine years my husband accepted my sickness of urine, but when he married another woman, he wouldn’t accept it anymore (*bai yarda*). He divorced me. I didn’t have any children, and my co-wife did. One day I asked my co-wife’s children to bring me water so I could prepare dinner. The children refused. I told them that if they didn’t get water, I wouldn’t prepare food. They didn’t go, and I prepared nothing that evening. My husband became very angry when he returned home. My co-wife told my husband to “divorce that sick woman” so that I could leave and get treatment somewhere. She said to him, “She is sick. She can’t stay with us.” My husband said, “Between you and me, today it is over. Here is your divorce.” I said I wouldn’t go anywhere until he gave me money for transportation. He finally gave me money, and I left. I was chased away.

As is the case with Salamatou, it is evident that “abandonment” and marital rupture is complicated by co-wives’ involvement. Often it is upon co-wives’ demands and encouragement that husbands resort to divorce, abuse, neglect, or mistreatment of their wives with fistula.

Like Salamatou, fifty-year-old Maou, also lived with fistula for thirty years. She explained how despite the good relationship she cultivated with her second husband, there was strife in her conjugal life due to tensions between her and her co-wife:

I was married young, before I saw my first blood. The first year, every night I ran away from my husband. I slept at my neighbor's house for a year. But in time, he and I came to love each other very much. Then he fell ill. He was sick for a couple of months; blood was coming down his nose. Then he was dead. After his death, I couldn't forget him, and I waited a long time before remarrying. I didn't love my second husband the same way. He was older, and it was a family marriage. There was a co-wife when I came to his house. But she left, and then he remarried. But she left too, and again, he remarried.

Despite Maou's early and forced marriage, she came to deeply love her first husband, and found it difficult to remarry. When she eventually resettled into a second marital household, it lacked stability. I asked Maou why all her co-wives left her second husband; I asked if he was not kind. She laughed, and said just the opposite. Maou pointed at herself, saying that her second husband divorced his co-wives because Maou had developed fistula during her first pregnancy with her second husband, for which her new co-wives mocked her and her "broken vagina":

My husband told her [Maou's co-wife] that she couldn't do that [mock Maou] and sent her away. The next co-wife was also bad. She mocked me. She said that I sold everything I owned to find health and still hadn't. She said I just wasted all my money... She is a really mean person. She was jealous because our husband loved me more, despite my sickness of urine. People in the village told him to leave me, but he refused. It wasn't his concern (*ba ruwanshi*). He continued to sleep with me. We slept on the same bed. I had seven pregnancies after the fistula. If it wasn't him, I would have been chased away. But he is patient and kind... At home, I use fabric to keep me dry, but I have a hard time getting enough fabric. Sometimes I use my husband's clothing—his extra pants or tunics—when he goes out and then wash them and dry them before he comes home.

Once, I used the fabric (*zane*) of my co-wife to sleep on. My co-wife was angry and wanted it back, but I had a fever, and told her I'd give it to her in the morning. Very early the next morning I washed and dried it and gave it back to her. She said it was ruined because my urine had touched it. She tore it up and threw it on the ground next to the mules. I was hurt by this, both because I needed fabric and because it was such an insult... She is not kind (*ba ta da kirki*)...

She would say to me, "you have an open vagina, that's why the urine pours out." She said I was dirty. She covered her nose when she walked by me. She wouldn't eat with me. She wouldn't eat the food I prepared. She would come and sit very close to me

just so that she could say that I smelled bad... She was jealous... She hated to see me clean, I kept myself so clean, if it wasn't for her, no one would have known! It was because of her that the whole village learned of my sickness. She told everyone! So, because of her, I couldn't go to ceremonies. I was afraid that people would look at me and mock me. I stayed at home and never left the house! My co-wife would go out frequently and would come back with things like meals or millet but would not even give me a single handful. Never! When our husband found out that she had told everyone in the village about my fistula, he sent her away. But after some time she returned. She's a bit better now because she understood that she had been punished by our husband.

Despite Maou's experiences with two loving and supportive husbands, Maou's story illustrates the ways in which co-wives can undermine networks of care and complicate women's coping strategies. While Maou's husband continued to invest in their marriage unabated and dutifully kept Maou's secret of incontinence from their community, allowing Maou to continue as an engaged and active social member, her co-wife strategically circulated information about Maou's "sickness of urine" in an attempt to discredit Maou and gain social power within—and outside of—her household. This tension demonstrates an important paradox, that often the stronger the commitment of a husband of a woman with fistula, the greater the jealousy of her co-wife (or wives) over material and emotional resources within the household. Thus, in households where women with fistula enjoy relationships with supportive to semi-supportive husbands, co-wives often deploy strategies intended to gain power over their ailing co-wives, mistreating women, undercutting women's coping strategies, and deteriorating their relationships with their husbands and members of their communities.

7.6 Waiting for Treatment and Marital Tension

Ironically, it is often fistula treatment seeking itself that can have the unintended side effect of inaugurating a marital rift. During the period of my research, women with fistula who were seeking surgeries had stayed an average of 6 months at their respective center without having received an operation (ranging from two weeks to six years) (refer to discussion in

Chapter 2, Figure 2.1). While no woman at the Danja Fistula Center had waited longer than three months, the same could not be said for fistula centers in Niamey.⁷¹ For example, Aishatou, a twenty-five-year-old Tuareg woman with fistula, had been waiting at a clinic for over a year and still had not even been consulted by a doctor. She lamented:

I cried for three days when my father told me I had to go to Niamey for surgery. I only knew Niamey from the radio. I didn't know anyone here. For me, Niamey felt so far away—like the end of the earth. After Niamey, I thought it was only the great unknown. And now, since I've been here, my life has gone by. My sisters and my cousins have given birth, some have married—but I wasn't there. I missed it all because I was here waiting.

Indeed, more than any other theme, waiting defined women's treatment experience. In a cross-sectional study of women with fistula in Tanzania, Mselle et al. (2011) highlight a similar relationship between treatment-seeking and marital tension. These authors claim, "Women stayed in the hospital seeking treatment for a long time. When they returned home, they found their husbands already remarried. Some husbands did not hesitate to say openly in the FGDs [surveys] that they left their wives because of the leaking" (Mselle et al. 2011).

Zara, a twenty-nine-year-old Hausa woman who had been at a Niamey center for nine months without having received an operation when I interviewed her, explained how her decision to seek treatment for her fistula was the direct cause of her divorce from her second husband: "He knew my problem [fistula] when he married me. He accepted it. But, I told him I would go to Niamey to look for health. He said to me 'if you go to the hospital in Niamey, consider yourself no longer my wife'. He said 'if you go, you won't be leaving as my wife'." Although Zara's husband accepted her incontinence, he refused to accept her prolonged absence from his household. Her decision to seek care came at the cost of her marriage.

⁷¹ It is important to note that these numbers come from my first interviews with women—many of whom continued to stay at the centers throughout my research period and even after my departure from Niger.

Dr. Lucien Djanikbo, a Nigerien fistula surgeon who claimed to have operated on 1,300 women with fistula since 1997, also noted that often it isn't fistula itself that causes divorce, but long separations due to treatment seeking:

You have seen that there are women who've left their homes two or three years ago, most husbands won't wait that long. There are some women who have been looking for treatment for 15 years. So, it is clear that it will cause a separation, and the husband of course will take another wife... If a woman waits many years at home without being treated, or if she is gone for a long time seeking treatment, it often causes divorce. Often, it isn't the fistula itself; it is the absence that can cause divorce... The management of fistula here in Niamey is a bit political, so women have to wait a very long time...

For many women in Niger, long absence results in weakened social networks as they become increasingly peripheral to social life back in their marital villages. Women are often consumed with anxiety during their time at centers, unsure when or if they will receive treatment or if the treatment will be successful. Women confide that they worry about their children, wondering if they have enough to eat, if they are being well taken of. They are concerned about their marital stability, knowing that each day that passes may bring them closer to divorce, or that their co-wives' exhortations may eventually prevail. As one thirty-four-year-old Zarma woman explained, "One day, even if your husband loves you, if you are not there, one day he won't be comfortable with you. He will listen to what your co-wife, his family, or your neighbors say." So, some women prefer to wait until they have birthed and weaned additional living children before seeking treatment, securing their positions in their households while carefully managing information about their condition.

7.7 Enduring Marital Bonds and Caretaking

While temporary or permanent marital rupture is common due to fistula, some husbands stay faithfully with their wives, seeing them through the period of illness or awaiting their return home from the hospital. Fasuma, a twenty-three-year-old Fulani woman from a far eastern

region on the border of lake Chad, married a Tuareg man from another village when she was 17. He came to her village looking for work and they fell in love. After a year, they were married. Fasuma's four pregnancies resulted in two second-trimester miscarriages and two births where both babies died within an hour after delivery. After the fourth labor, Fasuma was left with a fistula. She explained that although she hadn't returned to her husband's house since she fell ill, he had continued to support her, sending money, providing comfort, and visiting often: "he visits me every day at my parents' home. He brings me money and cloth and food. He sits with me in the afternoon and we chat." I asked her if she thought he would eventually leave her if she were not eventually healed. She responded, "No. I don't think he will leave me. He has been with me all of this time, since the beginning of this sickness. For some men, if he has the intention of leaving his wife when she gets sick, he will leave her at the very beginning, saying 'this woman has no use. She is broken and that's that'." Fasuma's husband regularly brought her cloth, perfume, money, and meat. He would lend her his cell phone when she traveled to hospitals so that she could keep in touch with him, calling the nearest phone booth in the neighboring village. Fasuma had been looking for treatment at three centers over the course of the preceding two years. She expressed concern for her husband, who had no other wife at home, and thus no one to look after him, to cook him meals, or to maintain his home. So, Fasuma voiced the desire for her husband to remarry: "I would like him to take a second wife because I have this sickness of urine and now I cannot be there to take care of him."

Similarly to Fasuma's story of mutual affection and caretaking, women recounted stories of husbands washing the urine off their bodies, laundering their clothes, consoling them, fetching water and firewood (traditionally a woman's task in the household), selling off livestock to pay for medicines, or butchering a sheep for them. Naio, a twenty-nine-year-old Zarma woman who

married a neighbor she loved at the age of fourteen, explained that over the past fifteen years she and her husband lived happily together: “In a household there will always be small arguments, small problems, but there will also always be solutions. My husband, he tries his best... He is a good man.” When Naio developed her fistula following her sixth pregnancy, her husband supported her, accompanying her to multiple hospitals, sleeping in hospital courtyards for months, while she sought treatment. After a failed surgery, she was weak, ill, and could no longer take care of herself or her household. Her mother came to stay with her, but soon after her mother was involved in a car accident, and Naio’s husband then tirelessly cared for Naio. “Because of the car accident, my mother could not take care of me anymore. So, my husband took care of me every day. Every day, he would bring me food, wash my body, wash my clothing. He even washed the rags I used for the urine,” she explained. While Naio’s or Fasuma’s stories of marital longevity and caretaking in the face of hardship and sickness were not the norm among women I interviewed, they were also not exceptional.

Mohamed was a thirty-eight-year-old Tuareg man from the north of Niger. His wife, Sadata, developed a fistula a year before and unlike the majority of women with fistula, she was treated exclusively through catheterization. I spoke with Mohamed at his house where he, Sadata, their daughter, and Sadata’s elderly father (Mohamed’s uncle) lived. Mohamed explained to me his experience dealing with his wife’s condition:

Every woman after she gives birth has some problems. But, after 40 days, she should become normal again. With Sadata, after three months she still couldn’t stand up by herself. I knew it wasn’t normal. I took her to the hospital and they said that her condition needed a surgery. I’d never heard of her sickness nor seen it—only Sadata. The doctor told me that Sadata’s operation would be a gift (*kyauta*), but I knew that she would need medicine for food and other things at the hospital. I went back to the village and sold five sheep and one goat. When I came back, she said that she was doing better. At [the center] they gave her food and soap—there was everything (*akwai kome da kome*)! She said that she could stay at [the center] until she was better, but I wanted her

home. I told her I would pay for her to take a taxi to go to her appointments and come home after...

I asked Mohamed how Sadata's fistula has affected him. Sadata walked into the small room, poured herself some tea into a small cup already half full of sugar, and laid down on the ground next to her husband. He responded:

I didn't pay attention to my worries or suffering because it wasn't anything compared to Sadata's suffering... Some husbands throw away their wives when they get sick. There are two reasons for this. First, they don't have a strong family connection like we do, so they don't have a strong relationship—Sadata and I grew up in the same house. I was there when she was born. Second, they didn't have strong mutual love (*soyayya*) to begin with, even before she was ill! But we have so much mutual love between us.

When Mohamed pronounced his love for her, Sadata laughed and playfully pumped her fists in the air in triumph.

Unlike Sadata and Mohamed, whose relationship had only bore the weight of fistula for a single year, Ladi and Adamou had dealt with chronic incontinence from fistula for twenty years. Ladi, a thirty-five-year-old Hausa woman, was deemed incurable by the fistula surgeons after 11 failed surgeries. After several miscarriages and years of trying in vain to conceive, Ladi was also deemed infertile. Because Ladi had spent so many years seeking care at a maternity hospital in Niamey, she was offered a job as a *filie de salle*, or a cleaning woman at the hospital. Largely due to her relationships at the maternity hospital and thus increased access to health care, Ladi was eventually able to become pregnant, and gave birth via an early prophylactic cesarean section to a healthy baby girl. Nine months after my first meeting with Ladi, I accompanied her home to meet her husband and co-wife.

Her husband (also a paternal first cousin), Adamou, a loving and animated man who worked at a Niamey market, spoke to me about how Ladi's health problems had affected her, him, their family, and their relationship, over the past twenty years:

We have been together 20 years this year. It is a long time. We will stay longer... It is only this year that God gave us a chance to have a baby. [My wife] had three pregnancies, and she miscarried three times. Three times she had a miscarriage, and then we figured out that God is the only one who can give a child. Jamilla [their child] is a star, a star who, not only here in Niger, but in the world, is very important.

I asked Adamou if he and Ladi were happy together, and he explained that he and Ladi were bonded through deep familial ties that were unbreakable, despite the troubles they had faced together:

She and I are like a person and their shadow. You can't be separate from it, even in a dark place. It's how we are. I trust in God, I know [fistula] is something that came from God. So, if you are living, you are not dead, you cannot despair... My people and her people are the same, and she is like my daughter. How can you abandon your blood? You cannot. It's like that. No one can bring any problem in this house between us. Me, her, and her co-wife, we are living in peace in this house. No problems. Everything that happened to her can happen to someone else.

Moved by his affection and unwavering support for his wife, I asked Adamou why in his opinion some men abandoned their wives when they developed fistula while others stood by their side.

Adamou sat silently, his hand resting on Ladi's, before explaining:

Some men, when the woman gets a problem, the man runs away from her. That kind of man doesn't have trust in God or anything. So if you have faith and you know what is supposed to be done you cannot run away from the woman. Stay with her! Then, she will trust herself and she will manage the difficulty easily. But if the woman has a problem and the man runs away from her, and her family does too—if no one cares about her, she will become crazy. She is going to become like a person who has a sickness, she will develop a problem of heart, and it will make her crazy.

I am making a call to people. Not just here in Niger, not in Nigeria, not in Mali, not in Gabon, but everywhere in the entire world. If a woman has a problem, the man should trust in God, and take care of his woman until God brings her health... It's the way that it's supposed to be... So if someone has problems, and people do not stay with him to help him, what will he do? The world will become sick. The sick will be many. The mentally ill will be many... I am calling to people. Thank God. [Ladi] is my daughter, and she is my wife... She and I are like a person and their shadow. You can't be separate from it, even in a dark place. It's how we are.

For Adamou, staying with Ladi throughout her struggle with infertility and her ongoing incontinence was motivated by faith in God, his own ethical compass, and love. Additionally,

situating Ladi both as his “daughter” and his wife, of his “own blood,” Adamou positioned family marriage as a protective mechanism that ensured ongoing commitment in the face of hardship.

Although Mohamed and Sadata’s and Adamou and Ladi’s relationships were particularly loving and supportive, they were not uniquely so. Complicating the dominant donor and media narrative of fistula induced marital dissolution, many women in my sample continued to live with often loving and supportive partners who neither rejected nor ridiculed them because of their illness, and some women (like Zina and her husband) even continued to engage in satisfying sexual lives after the development of their fistulas.⁷² These examples of care giving and marital faithfulness provide a counterpart to the prevailing grammar of masculine domination, domestic violence, and “forced” or “child” marriage so prevalent in discourse of sub-Saharan Africa.

7.8 Re-imagining Conjugal Landscapes

In this chapter I have challenged two marriage-related myths forwarded by the widespread fistula narrative. First, that fistula is a consequence of forced and early marriage; and second, that divorce and abandonment by women’s husbands are an immediate consequence of fistula. The attempt of the global fistula narrative to establish a causal connection between “forced” marriage and fistula is reflective of the way in which the popular media and donor narrative frames fistula as physical evidence of corrupted cultural practices that are seen to prey on girl-children. Early and forced marriages are understood as a single phenomenon and used interchangeably to convey moral indignation at the premature and unjust sale of young girls into

⁷² In a cohort study of 120 women with fistula in Niger and Mali, Maulet et al. (2013) note that 13 women with fistula in their study got married during the study period, including 7 who remained while still incontinent—revealing the presence of marital and sexual bonds despite fistula and incontinence.

sexual activity and domestic responsibility; however, they are not the same. Obstetric fistula is correlated to the quality and accessibility of obstetric care, *not* the age of marriage, *nor* the desirability of the union to the woman, *nor* even the age at first pregnancy.

This fixation on the early onset of sexual activity of black bodies (specifically, fistula bodies) evidenced in the fistula narrative reflects a Western preoccupation with the idealized innocence of girl-children (and the violation of their innocence evidenced by their sexual activity), rather than an actual problem of “early” sexual activity. Rather than depicting meaningful causal relationships, the focus on “forced” marriage in the fistula narrative works to further semiotics of cultural failure, positioning aspects of “bad culture” as a cause of fistula only to further highlight their “badness.” Yet, as demonstrated, fistula cannot be linked to forced or early marriage.

Regarding the myth of marital divorce and abandonment catalyzed by fistula, fistula affects marriages in diverse and complex ways—for some women resulting in divorce, for others solidifying bonds of support and caretaking, but more frequently resulting in liminal spaces where conjugal futures are uncertain, contested by co-wives, and capitalized upon by both husbands and wives. Frequently women in my sample were neither substantively married nor officially divorced, instead “separated” and thus occupying temporary or protracted spaces of marital liminality in which the woman and/or her husband were both negotiating the next step in their marriage, its meanings, and its public appearance. Yet, despite the great diversity of meanings in these marital separations, the donor and media fistula narrative labels all women whose fistula caused marital disruption as “abandoned.” Not only is this an inaccurate term for the vast majority of women, but it also strips women of their agency in their conjugal futures.

Instead, fistula must be understood within a context of constrained, highly structured marriages where opportunities for relationship futures are narrowly defined, and how well a marriage can absorb the shock of illness and injury is highly dependent on variables such as family support, number and rank of co-wives, length of absence for treatment seeking, and a woman's initial desire to have married. Indeed, as I have demonstrated within this chapter, these factors may be more predictive of marital outcomes following a woman's development of a fistula than her relationship with her husband alone. Even when husbands are supportive, co-wives have the power both to protect and to harm a woman's marital relationship following the development of her fistula, proving that relationships to women with fistula's co-wives are complex, fluid, fraught with anxiety, and potentially destructive to household stability.

Chapter 8

Local Understandings of Vaginas and Sexuality: Examining *'Dan Guriya* and Other Gynecological Abnormalities

Central to marriage and reproduction are local norms of healthy sexuality and normal vaginas. When women deviate from these norms, their (or their families') quest from normalcy can result in fistula—caused by a local surgical procedure performed in villages by “barbers” in attempts to restore women’s sexual desire and blocked vaginas.

For some women, fistula was not developed during labor at all, but as the consequence of a treatment for a local gynecological abnormality known as “*guriya*.” Examining these cases highlights how a vast array of gynecological and obstetrical health concerns are often rendered invisible by the shadow of fistula.

Within my first few months of fieldwork, I heard a lot of passing comments about something Hausa women called “*'dan guriya*” or simply, “*guriya*.” None of my Hausa dictionaries were of any use (*guriya* literally translates as “cotton seed” while *'dan guriya* is “little cotton seed”), nor were the educated (and relatively cosmopolitan) Hausa nurses, clinicians, or even my research assistants. Most of them had never heard of “*guriya*” outside of the context of farming. I performed literature reviews and internet searches in vain. Yet, the more I knew about *guriya*, the more women were willing to tell me. In fact, nearly all of the Hausa women with fistula I talked to (and many of the Zarma, Fulani, Kanuri, and Tuareg

women as well) ⁷³ had heard of *guriya*, and most women cited it (or rather the local surgery to correct it) as a potential cause of fistula.

After long hours with many embarrassed women (dismayed by my anatomical ignorance, no doubt), I discovered that *guriya* is something that some girls are born with. It is a small piece of flesh within (or just outside of) a young girl's vagina that grows as she grows. If it is not excised during infancy or early childhood, women believe that it will eventually block the vagina entirely, impeding a woman from consummating her marriage. Some women told me that it starts off the size of a pebble, some compared it to a grain of sorghum (or a cotton seed, as its name suggests), while others likened it to a "little, pointy piece of meat" or a "small chicken heart" (a rather unhelpful analogy for someone with as little fluency in the anatomy of domesticates as myself).

When a *guriya* is not detected and excised early, it can wreak havoc on a woman, her family, and her marriage. Men are typically so ashamed that they cannot consummate their marriage—ashamed that they married someone who "isn't even a woman" that they might not tell anyone for years. But, eventually, the lack of a pregnancy betrays their secret and the bride's family sweeps her away, bringing her to the *wanzami*—the local barber who also serves as the village surgeon. If after an examination the *wanzami* believes that the woman has a *guriya*, he uses a homemade iron knife to carve it out (I am told that he dulls the pain with a paste made from the seeds of a bush tree). If all goes well, he then sends her home to consummate her marriage the same day. If a girl's *guriya* is not caught early (well before puberty), then what would otherwise have been a relatively risk-free intervention, the excision of a small lesion, becomes fraught with danger. Women's stories depict a *wanzami* who cuts haphazardly and without precision in a grown woman's vagina, attempting to carve out the expansive papule and,

⁷³ Zarma women referred to "*haabize*," which also literally translates as "cotton grain."

in the process, often nicking or entirely severing the woman's urethra, or other continence mechanisms, potentially causing a fistula.

Confused about the biomedical (or psychosocial) etiology of *guriya*, I probed further—
“Can everyone see the *guriya*, or just the *wanzami*?” “Does a *guriya* actually stop a woman from being able to consummate her marriage, or does it just stop her from having the desire to do so?”
“How frequently are little girls born with *guriya*?” “Do girls or women with *guriya* ever appear more masculine in appearance than other girls or women?” “Are *guriya* painful or tender to the touch?” “Do women in forced marriages tend to have *guriya* more often than women who marry for love?” The answers were often contradictory and unsure, but revealed complex understandings about women's sexual obligations and sexual desires.

Kalthumi, a twenty-five-year-old Hausa woman, explained that neither she nor I could see *guriya*, “You can't see it, you only know it is there if a woman runs away from her husband.”
Ramatou, a thirty-five-year-old Hausa woman, explained that her oldest daughter had a *guriya* removed when she was eight years old. I asked Ramatou how she knew her daughter had *guriya*, she explained, “If she peed in the shower, the pee would spray all around, but if her little sister peed it would make a little hole, it would fall in a straight line.” Indeed, several women explained that although the untrained eye could not “see” *guriya*, it could be identified by the way in which a young girl urinates, her urine would not “fall in the same spot,” but rather would “spray all over.” Conversely, other women told me that, “anyone who looks can see the *guriya*.”

Salamatou, a twenty-eight-year-old Hausa woman, explained that:

Guriya is something in the vagina that some women are born with. It stops women from accepting a husband. Some women marry and stay with husbands for a long time without having sex. They cannot. The husband is ashamed to say that he hasn't had sex with her. But eventually he will ask himself, ‘Is she even a woman?’ He might become angry and approach the woman's family. The woman's family will then take her to a *wanzami* to

verify if she has *guriya*... When [the *wanzami*] takes it out, she will then finally accept her husband.

Frequently women phrased their responses in a similar way as Salamatou, explaining that women with *guriya* would not “accept” their husbands, creating ambiguity as to if women’s refusal was physical (they could not “accept” his penis into their vaginas) or social (they could not “accept” his role as her husband). I asked Salamatou if *guriya* actually blocks the vagina and thus impedes intercourse or if it hampers sexual relationships by diminishing a woman’s sexual desire. She explained that it was physiological, “There’s no path into the vagina (*babu hanya*).”

However, other women believed that *guriya* hindered sex by changing the woman psychologically rather than physiologically. Many times I was told that women with *guriya* “refuse” their husbands, euphemistically explained by many women as, “If he is outside, she is in her room. If he is in her room, she is outside.” A’i, a twenty-three-year-old Hausa woman, explained that, “If a woman doesn’t want to be touched by a man, she probably has *guriya*.”

Habsu, a twenty-five-year-old Hausa woman, explained that, “A woman with a *guriya* doesn’t want to sleep with a man. She runs from him.” In an attempt to decipher if *guriya* hinders a woman from engaging sexually with her husband because it affects sexual desires or if it actually changed her anatomy, I asked Habsu if a woman with *guriya* could be raped. She thought for a minute before replying, “No. She will run away and cry and fight with such force that she won’t be able to be raped.” Habsu’s response was unexpected, suggesting that although *guriya* did not change women’s anatomy significantly enough to block penetrative vaginal intercourse, it changed women’s constitutions of desire so dramatically that Habsu couldn’t imagine a woman with *guriya* accepting sex, even by force.

Ade, a forty-year-old Hausa woman, responded with equal ambiguity, “At the time of marriage, a girl can’t have sex. If a woman wants to sleep with her husband, she can’t. The

problem is *guriya*. It is like she doesn't love him. A woman I know got fistula from *guriya*. She told me that she didn't want to be touched by her husband. She loved him, but the problem was the *guriya*." For Ade, the notion of love could be decoupled from a woman's desire for sex in the pathological environment of a vagina with *guriya*.

Safia, a twenty-seven-year-old Kanuri woman, explained that, "If [*guriya*] isn't caught when she is young, people don't know [about *guriya*] until a woman runs away from her husband, then they will call the *wanzami* and cut it." "How can you know that she isn't running away from her husband because she doesn't love him or because she is afraid of him, and not because she has *guriya*?" I asked Safia. "Those that have *guriya*, it isn't only her husband that she is afraid of, it is all men. As soon as a man comes next to her, she runs away, even before she was married." "So, if a woman doesn't like men in general, she has *guriya*, but if a woman runs away only from her husband, it is understood that she fears him and it isn't *guriya*?" I clarified. "No," Safia said with a laugh, "Even if she runs away from her husband alone, people will still wonder if it is *guriya*."

I asked Fanta, a twenty-five-year-old Hausa woman, how you can differentiate a girl who runs away from her husband because she is afraid from a girl with *guriya*. Fanta explained that, "You call tell if it is *guriya*, for example, if a husband is patient but the girl continues to run away, so he divorces her, then, if she remarries and she does the same thing, people will know that it isn't that she is afraid, but that she is sick. They will know it is *guriya* and not fear." While some level of fear, anger, sexual avoidance, and desire to flee from a marriage was considered normal behavior from young brides, when these behaviors continued for extended periods of time, when they extended to all men, or when sexual avoidance was coupled with love, these behaviors became pathological and *guriya* was suspected.

Women seemed to be telling me that *guriya* could be diagnosed when a woman transgressed the boundaries of normal sexual resistance, some of which was expected (and, to some degree, a desirable enactment of piety) of young women and new brides. But was *guriya* the transgression itself or did it in fact parallel a physiological aberrancy with a Western/biomedical diagnosis? Could a fleshy abnormality be seen (and if so, by whom), or was abnormal sexual desire sufficient diagnostic evidence?

Unsatisfied with the ambiguity, I decided to take my questions to the local expert—referred to me by both the chief and the local midwife who I had come to know in a small village outside of the Danja Fistula Center. The *wazami* was eccentric. He insisted that he wasn't a day older than 19, though the ten children he sired and the wrinkles around his eyes suggested otherwise. He prodded my leg inappropriately. He repeatedly demanded large sums of money from me. As a *wanzami*, his job description was expansive: conduct male circumcisions, take out the uvulas of infants, carve out wisdom teeth, make medicines from bush plants, heal “sunken-in” heads, conduct scarifications, restore bodily imbalances, extract tumors, cut out *guriya*, to name a few. And also, to cut hair. He emptied out his dusty leather bag, packed full with desiccated animal parts, horns used to suck “bad blood” out of bodies, hand sewn leather amulets, dried herbs and seeds, ancient iron rods, new and sterilized straight razors, sundry powders and pastes, and an electric beard cutter from the 1970s—after all, he was a barber.

After several attempts to probe I was still unsure if anyone could actually *see* a *guriya*, or if it was symbolic—a somatic manifestation of aberrant behavior—such as refusing a husband. “How do you know a woman has a *guriya*?” I asked the *wanzami*. “Simple,” he said to me, “if a girl doesn't like to be flirted with, or shows no interest in men, she probably has a

guriya.” If she doesn’t want to get married, if she isn’t kind to men, if she isn’t interested in their physical proximity or their sexual advances, then she probably has a *guriya*, he added.

The average age of marriage in Niger is 15.7 (DHS 2012), and often girls from rural areas are married much younger (many women I spoke with told me that they didn’t reach menarche—their first period—until two to four years after their weddings). Thirty-four percent of women with fistula I came to know married at or before the age of fourteen. Even if one is a consenting adult at the time of marriage, even if a woman has a “love marriage” (whereby she actively participates in her choice of husband), when it comes to conjugal futures, Nigerien women’s agency is extremely constrained (as discussed in the previous chapter). Women typically have very little choice in whom they marry and choosing not to marry at all is realistically not an option for most women.

Given this, could *guriya* simply be a more palatable explanation for female sexual resistance, I wondered? One that doesn’t call in to question existing structures, expectations, or cultural norms, but rather pathologizes aberrant behaviors? I began to think of *guriya* as a distant parallel to the early 1900’s diagnosis of “hysteria” or “frigidity” in the West. Perhaps *guriya* even served as a mechanism to dissuade women from protesting arranged marriages? The knowledge that resistance is futile (and may even result in non-reversible bodily damage) could act as an effective deterrent for young women unhappy about a union they found themselves in (at the risk of being too functionalist in my brainstorming). Or, was there a physiological explanation? Did *wanzamis* perform hymenotomies when they removed a *guriya*? Or could *guriya* be some sort of catchall for unusual abnormal genitals, vaginal growths, congenital abnormalities, intersexed conditions, anything from abscesses to cancers to benign cysts?



Figure

8.1: (from top left clockwise) the *wanzami* shows the tools he uses for surgeries, the *wanzami* sterilizes his instruments before performing a circumcision, the *wanzami* shows the bean pod which is used for pain reduction following surgeries, the *wanzami* shows his hair clippers, beans pods used for pain reduction, the *wanzami* simulating a male circumcision on a three-year-old boy.

Without much clinical knowledge or first-hand experience, I relied on diagrams sketched with a stick in the sand, on hearsay, on the story of a cousin of a friend, on euphemisms. I drew conclusions from silences, from giggles, from expressions of shame. Ultimately though, I cobbled together theories and hypotheses regarding the relationships between women’s bodies, local interventions, and symbolic meanings.

8.1 Sadiya’s Story: The Quest for Normalcy, The Unattainable “Healthy Vagina”

Sadiya, a twenty-year-old Hausa woman, did not get her fistula from a difficult labor. In fact, despite having been married for three years, Sadiya had never been pregnant. She had never even seen her period. When I spoke to her, Sadiya, in fact, was still a virgin. Sadiya represented a small and often invisible population in Niger’s fistula centers—women with fertility problems, large fibroids, ovarian tumors, severe genital tract infections, or in Sadiya’s case, ambiguous genitalia, who find their way to fistula centers. Often these women are leaking because their reproductive or genital abnormalities were treated by village surgeons or barbers

(*wanzami*) who indiscriminately cut at her genitals—leaving her with her original problems often unaddressed, but also with fistula caused from the surgical cutting.

Sadiya was one of three women in my sample who was treated in her community by a *wanzami* for *'dan guriya* in order to restore reproductive normalcy. In the process, too much flesh was removed from Sadiya's vagina, resulting in unintentional damage to her continence mechanisms and causing fistula.

Sadiya came to know that her vagina was not normal when she was still a child. Showing me the tip of her thumb, she explained that something came out of her vagina, something that other girls did not have, "When I would shower with my friends, I could see that I looked different from the other girls. No one else had *guriya* but me." Looking at her hands, she explained, "Some girls are born with *guriya*, but it is taken out early. With me... well... I don't know why mine wasn't. I was told that the *ungozoma* [midwife] washed me and verified my body but she didn't see anything."

Sadiya explained that the *guriya* grew over the years, eventually closing her vagina, "When I was young, it looked like a grain of sorghum, but with time it got bigger. Then, it closed everything up; there was no path (*babu hanya*)."

At the age of 15, Sadiya was forced by her father to marry a paternal cousin. For three years, Sadiya did not consummate her marriage. She still had not seen her first blood. Every night, Sadiya ran from him, "As soon as my husband came in my room, I went out. When he came out, I went in the room. I didn't want him to touch me, so I'd sleep outside until the first prayer." She explained that she came to like him well enough, and developed a caring—even loving—relationship with him during the day. It was only during the night that she could not be near him, "He let me be, he wasn't angry because he understood that I was just a child. He even

pitied me.” But, Sadiya knew that the problem wasn’t her age, “the problem was *guriya!*” she averred. “When I was with my younger sisters or friends, I would hear them talk about their husbands, they did this or they did that, they’d say. I asked myself why I couldn’t do the same things as them. I couldn’t talk about the same things. I was ashamed. I couldn’t tell anyone my problem. It was shame that I felt! I couldn’t sleep with him. (*Kunya naki jin! Ba ni iya kwance da shi*).” But, her husband was patient, and either out of kindness or shame, or as Sadiya suspects, a mix of the two, for three years he never told anyone that his wife was still a virgin.

“If a women has a *guriya* she won’t accept that her husband touches her, that’s how he’ll know that she has *guriya*,” Sadiya explained. I pushed Sadiya, trying to understand if a *guriya* physically obstructed sexual intercourse, or if the obstruction was more symbolic, affecting a woman’s desire rather than her ability to consummate the marriage. After a few minutes of me asking the same (rather explicit) questions, Sadiya seemed exasperated, “If a girl has *guriya*, she can’t accept her husband. A girl wouldn’t accept to be close to him, or to let him touch her. Really, if a woman has it, she doesn’t want to be near a man, she doesn’t want to be touched.”

After three years, Sadiya’s husband could not stand it anymore. Sadiya explained that her husband confided in a friend, and that the friend then sent his wife to speak with Sadiya. In tears, Sadiya confirmed, saying that she knew her vagina was not normal. The woman accompanied Sadiya to her father’s house, urging Sadiya to admit her problem to her stepmother. “I told her, but she didn’t believe me. She said that it must be false. She didn’t understand how we could be married for so long and not have spent the night together. She told my father and they were sure that I was lying. They called my husband, and it wasn’t until he confirmed that they believed me.”

Once the rainy season passed and the agricultural work was finished, Sadiya's father brought her to a village far away to see the *wanzami*. Overcome with shame, they told everyone in the village that they were going to visit family. Her father hoped that the *wanzami* would cut out Sadiya's *guriya* and return her to her husband before anyone suspected that she had a problem. They stayed in the small hut of the *wanzami*. She explained that he laid her down on a mat woven from millet stalks, he gave her nothing for pain, and two men held her down as he cut out the *guriya* from inside of her. I asked Sadiya if the experience was shameful, having three men look at her genitals. She laughed, "Yes, I was ashamed. But, those who are sick are considered like a crazy person. Anything they are told to do to get better, they will do. Even if these men saw me walking down the street, back to normal, they wouldn't recognize me!"

But, the procedure did not work. "When the *wanzami* came and cut me, instead of bringing blood [her menstrual cycle], it brought urine [fistula]." When Sadiya awoke the next morning, she found herself in a puddle of her own urine, blood, and puss. The *wanzami* told her and her father that it would stop on its own, and pocketing the 40,000 fcfa (approximately \$80 USD) he put them in a taxi and sent them home.

While the infection cleared over time, the leak neither stopped nor diminished. When Sadiya went to a local health center, the nurse examined her, shook his head, and said that there was nothing he could do for her, "The nurse looked at me and said my problem was stronger than he. He gave me papers and referred me to a hospital." In the next two years, Sadiya went to a dozen hospitals and clinics, each time she was met with clinicians who shook their heads, scribbled notes on papers, and referred her elsewhere. Ultimately, the long chain of referrals led her to the capital, "The doctor asked if I had seen my period. I still had not and he said that they

would need to intervene for both my period and the fistula. He said he wasn't able to help me and sent me to Niamey.”

Sadiya spent a year at home, moving seamlessly between biomedical clinics and local healers looking for cure. Local healers (*boka*) gave her teas made from herbs and tree bark to drink and bathe in. Tuareg healers, known for their powerful command of medicinal barks and roots, made vaginal suppositories and ointments for her. “I used all of my money (*Na kasha kudi*),” she recalled. Because the *wanzami* cost so much, she felt that she couldn't ask her father for any more financial help, “Because my father already spent so much, and then he didn't have a job, I couldn't ask him for more. He already had a family to feed.” So, Sadiya sold all of her things. She sold the dishes she received for her wedding. She sold the one sheep she owned. She sold all of the furniture in her small room. And when she had nothing more to sell, she gave the *boka* her last fabrics in exchange for more local medicine.

For the first year that she lived with fistula, her husband had migrated—working in a neighboring country to make some money. When he was gone, she never told him about her fistula, “He would call and ask how I was healing [from the *wanzami*'s procedure]. I told him that I was better... Really, I was ashamed. I feared that if I told him, he would never return.” Sadiya stayed with her husband's parents during that year. And although her mother-in-law was her aunt, she was unkind, “Every day she said that she wished that her son was there so that he could remarry and divorce me. She said that before the fistula I ran away from her son, so I deserved my sickness... She told me that I was dirty. She'd say I smelled bad, smelled like a camel!” Her mother-in-law insulted her, hit her, and withheld food from her. And although there was no blood relationship between them, her father-in-law tried to protect her from the angry words and actions of her aunt. But her father-in-law was ultimately powerless against the

constant pressure her mother-in-law put on her husband, and eventually, her husband ceded to his mother's will and divorced Sadiya. "My father-in-law tried to stop her, by he couldn't. He cried the day I came to get my things... She used sorcery to make my husband accept the divorce. At first, he [my husband] consoled me. He said that it was my destiny; that it came from God. But the medicine affected him, and so that was that."

Sadiya had been at the fistula center for over a year when I met her. She finally underwent surgery, and luckily, she attained continence. Still, Sadiya did not want to return home. Her most pressing problem still had not been addressed. At the age of 21, Sadiya has still not seen her period. Sadiya's clinical file was dotted with notes like: "no vagina," "congenital malformation," "absence of uterus," and "penile hypospadias?"⁷⁴ Also written in her file were notes about the fistula etiology, one note scribbled in the margin, "*yankan djichiri?*", referencing "*yankan gishiri*," or "salt cut," known to have been practiced in northern Nigeria in the cases of obstructed labor (Wall 1998).⁷⁵ Another note read, "From birth to today, she has never seen her period. Her parents brought her to a *wanzami* who, by a vaginal incision, removed from her a '*dangouria*' (Hausa word), that's when the urine started to leak," reflecting the limited knowledge many urban Nigerien biomedical practitioners have about '*dan guriya* often

⁷⁴ Hypospadias is a birth defect of the urethra in males whereby the urethra is abnormally placed.

⁷⁵ '*Dan guriya* is distinct from the better known intervention (said to be common among the Hausa of Nigeria) of "*yankan gishiri*" or "salt cut" which is performed by a local midwife (*ungozoma*) in the case of an obstructed labor (Wall 1988). The "*gishiri* cut," administered to women suffering from obstructed labor, is an intervention aimed at perforating an imagined film covering the vaginal opening thought to result from a salt-sugar imbalance. Because this impenetrable layer is believed to block the normal birth of a child, an *ungozoma* uses a sharp object, such as a knife or razor to incise a woman's vaginal canal during an obstructed labor, thereby perforating the salt layer and allowing for the passage of the infant. In some cases, as with the first pregnancies of particularly petite women, a *gishiri* cut is used to widen the vaginal canal (Wall 1998). According to Wall and colleagues, this practice may lead to a wide array of consequences, including hemorrhage, sepsis, pelvic damage, or fistula (2004). '*Dan guriya* is distinct from '*yankan gishiri*'. Most notably, women with *guriya* cannot become pregnant as they cannot be vaginally penetrated. However, '*yankan gishiri*' is not practiced in Niger. According to Vanderputte (1985), "traditional practices like '*gishiri* cut' (incision of the anterior vagina; wall) in neighbouring northern Nigeria, are, at least to our knowledge, inexistent in Niger" (307). No Nigerien woman I spoke with had heard of the practice.

conflating it with unrelated local practices from Nigeria such as *'yankan gishiri* or other forms of female genital cutting.⁷⁶

After an examination, women like Sadiya are often excluded from the list of surgical priority of fistula centers, probably because their problems are too big, too complex, or too unrelated to be treated at fistula centers. But frequently, none of this information is transferred to the woman. As each surgical team passes through, and as the months pass by, these wonder why they are never operated on. They don't know why their bodies are different. They are never told why they aren't chosen. Across Niger, fistula centers often serve as catchment areas for women with all sorts of fertility and gynecological problems—women who are not sure what they have, for whom diagnostic categories do not remain in stark division.⁷⁷

8.2 Zara's Story: If Not a Woman, Then "Almost A Man"

For Zara, a twenty-nine-year-old Hausa woman, her recto-vaginal fistula was just one of many of her concerns. Although Zara had been married twice, she had never given birth. In fact, like Sadiya, Zara was still a virgin. "There is something wrong we me," she told me one afternoon, as she wiped away a tear that rolled down the side of her cheek with her bright red hijab. Zara went to four *wanzami* over the course of nine years, searching for a remedy for her condition, "but, the fourth *wanzami* [accidentally] 'touched' my anus and cut it in two pieces. So, when I needed to defecate, one part came out where it ought to, and the other part came out through my vagina."

⁷⁶ Female genital cutting is rarely practiced in Niger and largely unknown among the dominant Hausa and Zarma ethnic groups. The WHO (2015) estimates that there is only a 2.2% prevalence rate of female genital cutting in women aged 15-49.

⁷⁷ In the fall of 2014 when I returned to Niamey to conduct follow-up research, Sadiya was no longer at the fistula center. Her friends and center staff all reported that Sadiya had found a husband and moved with him to a coastal West African capital city. Since moving, she had returned once to the center, still looking for treatment for her fertility "original" or "unresolved" problems, as they were euphemistically called. According to her friends, Sadiya did not tell her new husband about her problems, and it was causing them strife. Sadiya was unhappy in the marriage, and lonely in her new home, they told me.

When Zara was about ten years old, she told me that a small piece of flesh about the size of a sorghum grain, grew outside of vagina. “It hurt and I told my mother, but she wouldn’t listen to me. Eventually, the piece of flesh disappeared. It entered into my vagina. Inside, it developed and it grew. Like a squash vine, it spread until it covered the opening, until there was no more entrance into the vagina (*babu hanya*),” Zara explained.

“Since I was a child, I knew that something wasn’t right. My half sister and I would shower together, and I showed her. I told my mom that she didn’t have the same thing as me, but she wouldn’t listen. She said to me ‘I put you into this world! What could have happened to you that I wouldn’t have known?’ So, she ignored me.”

Zara was left unexamined and untreated until her marriage. After she was married, Zara returned to her mother’s home to explain that she wasn’t able to consummate her marriage. “She still wouldn’t listen. She said to me that if it were true, my husband would have come to tell her. But he was so ashamed, he didn’t say anything.” So, for two years Zara and her husband both suffered silently, too ashamed to admit that their marriage was sexless.

Zara’s husband eventually told an uncle of theirs. “This uncle spoke with my parents. My mother admitted that I had tried to tell her many times, but that she didn’t believe me.” Zara was brought to a hospital in Nigeria. There they diagnosed her, but when I asked her what they told her it was, she shrugged and explained that she couldn’t remember, that they did not explain it, that they used words she had never heard before. She explained that they took something out of her vagina that was “like a leaf,” but that she “doubted they did anything at all.”

Zara returned to her husband, but there was no change. Almost three years of sleeping in the same bed, they still couldn’t consummate their marriage. It was only then that they called the first *wanzami*, beginning a long and painful string of local surgical remedies. The first *wanzami*

came to her parent's house. Zara remembered that he brought an old box of tools and a plastic mat. He placed the mat in the shower and called three men, her husband, his friend, and her father, to hold her down while he performed surgery. He gave her nothing to dull the pain, and using the same iron knife he used to perform facial scarification (*shashawa*), he removed a piece of flesh from her vagina.

The procedure didn't work, and soon after Zara's family called a second *wanzami*. Another piece of flesh was removed from Zara's vagina, once more blood pooled beneath her, once more Zara couldn't walk for weeks due to pain, and once more, the surgery was unsuccessful in allowing Zara and her husband to consummate their marriage.

Eventually, Zara's husband felt overwhelmed by her problem and decided to walk away from their marriage. "He never treated me poorly. The day he made the decision to divorce me, he called me and said that he tried his best. He wished me well and said he hoped that I'd be fixed. It was the only problem between us... He said that maybe if I was fixed, we could remarry. He loved me very much."

Back in her natal home, Zara continued her quest for normalcy, traveling between biomedical centers and the homes of local healers and surgeons. Zara and her parents called two more *wanzami* over the next two years. The fourth *wanzami* did not believe that Zara had a *guriya*; he did not know exactly what she had, but he said he could fix her problem anyway, "The first three *wanzami* believed that I had *guriya*. But the fourth *wanzami* knew it wasn't *guriya*, but he cut me because he wanted money. It wasn't right. In the hospital, some said that my sickness was above their abilities, so they referred me. But he just cut," Zara said angrily.

Zara recalled how different the fourth *wanzami*'s surgery was from the others, "He kept cutting and cut much more than the others. He cut out three big pieces from my vagina until he

also cut the anus... The mat was entirely covered in my blood. There was so much blood and pain—I couldn't see.”

After a few days, she saw that feces passed through her vagina, and that “wind” was exiting from there too. She told her mother, who told her father, who went and confronted the *wanzami*. The *wanzami* said it would pass, but it didn't. “Are you angry with the *wanzami*?” I asked (one of far too many questions so obvious that it probably ought not have been asked). “No, it was just my destiny,” she replied simply.

“I wasn't happy. I smelled bad. When I went to the toilet, it came out of the wrong hole. When I was with people, air would come out from my vagina and I couldn't do anything about it. I felt so much shame. But, I couldn't do anything about it.” Zara hid her fistula from everyone but her mother and father. Even those close to her didn't know. “I was afraid that if the others knew, they would run away from me—they would be disgusted,” Zara admitted. “In the village, everyone talks. Because marriage is sacred, if a woman is divorced, everyone asks why... When some found out about me and my problems with my husband, they told others. Many were shocked and said that my husband had been very patient.” Because Zara already felt socially discredited due to her inability to consummate her marriage, and resultant divorce, she and her parents guarded the secret of her incontinence carefully—telling no one and engaging in a strict schedule of dogged self-care while she sought surgical repair.

“I've been to so many hospitals looking for medicine,” Zara recalled. She spent three months in Maradi, one month in Zinder, one month in a northern Nigerian hospital, but “in all of these hospitals, the doctors would tell me that my case surpassed their abilities. They would look at me and tell me that my case was too complicated for them.” Four years after the onset of her recto-vaginal fistula, she travelled across the country to the National Hospital of Niger in

Niamey, hoping to find solutions for both her problems of incontinence but also her “original problem.” She explained, “What brought me to the hospital wasn’t the fistula, but the original problem. But, they only operated on me for the fistula.” Zara’s fistula operation was successful, in that her fistula was closed and she regained continence. Still, for Zara, having to return home without a vaginal opening, without a healthy vagina capable of receiving a penis and thus delivering a baby, she considered the operation far from successful. For Zara, her fistula was an uncomfortable, shameful, and embarrassing side effect of her far more serious “original problem.” I asked Zara how her life changed once her fistula was repaired. She explained, “Because it wasn’t my real problem that I was operated for, really, nothing changed.”

After her operation, Zara returned to her parent’s home, and eventually she remarried. “People told him not to marry me, but he loved me and he accepted me as I was. People said to him, ‘She is almost a man.’ Some would even say, ‘No, she *is* a man’.” Her new husband already had two wives, and although her co-wives didn’t initially know about her problem, eventually they heard gossip. “When people came to the house from my village, they asked, ‘This girl married here, is she fixed or is she not fixed?’ They gossiped between them, and soon they knew. They would then ask between them, ‘Is she fixed?’”

Eventually, Zara’s inability to engage sexually with her second husband became problematic. Her husband began treating Zara differently from his other two wives, opting to give goods not to his wives, but instead to his children:

He began to call the children and say that the things he brought from the market were only for them, the children. For the other wives, they would get their part because of the children. But I wouldn’t. When I saw that, I understood that there was a problem between us... I said to him that before we married I was clear about my problem, but it was clear that he didn’t love me anymore. So, I told him that I preferred to leave because he mistreated me. Because he wanted to take another wife, mistreating me was his way to chase me away.

Zara had problems with her co-wives, but understood that the problems she had with them were really just a reflection of the relationship she had with her husband:

I understood that the problem wasn't with my co-wives, but it came from my husband. You see, if in a house a husband and wife get along well, even if there are problems between co-wives, the co-wives will respect each other. But, if there is a problem between husband and wife, the co-wives will profit from it. They will say unkind things to the woman who is out of the husband's favor.

I asked Zara what her co-wives said to her, but she shook her head, and responded, "Some of those things I can't even say out loud. A co-wife, even if you are well and healthy, she will always find something to hurt you with—something unkind to say. And for a woman who has a problem like mine..." Because they learned that Zara did not have a "normal" vagina and thus could not engage sexually with their husband and provide him with children, Zara's co-wives insulted her and questioned her identity as a woman. "They often said if it wasn't their husband who had taken me as a wife, no one would have. 'Who would want to be with a man?' they'd ask. They'd say, 'If we were to count the women here, you would not be among them!'"

"Some people would say to my husband that because I couldn't have children, he was feeding a man. Some people didn't believe that I was sick. Others always found something to say about me, something to insult me about. They said that I had this problem because God judges people's characters and punishes those who are bad. If I didn't have loving parents, I would have considered suicide."

Zara decided to return to Niamey's fistula centers to seek an answer to her "real problem." She told her husband that she was leaving, and with a nod of his head, he said, "Have a good voyage, but if you go, you won't be leaving as my wife." Zara gathered her few things into a plastic basin and took the next taxi to Niamey.

“They told me that a piece of my uterus was coming out of me. They told me that it would have to be taken out, that I will never be able to have children. I didn’t want it, but my parents said that it was better that I had good health than having the two problems of infertility and bad health.”

With few options, the most optimistic being a hysterectomy, Zara had lost hope. “Now my life is broken. Even if they take out my uterus, I can’t be happy. I must put myself at God’s mercy. Only he knows why I have this problem... I will be patient and not hope for anything,” tears rolled down Zara’s cheek as she spoke. Zara turned her head away from me as tears continued to roll silently down her face. “There are sick people, there are infertile people, but God created all of them. This is what I tell myself...” she said quietly as she buried her face in her hijab.

* * *

The local notion of *guriya* is both an explanation for unhealthy vaginas—an umbrella concept covering myriad vaginal growths, congenital deformations, and intersex conditions—and a less anatomically localized condition of desire in which a woman’s proper sexual response is altered, resulting in her inability to welcome a man’s sexual advances. *Guriya* is ideally treated in very young girls, as complications from the local surgery are believed to be minimized when the *guriya* is smallest—during infancy. When unnoticed and thus untreated, Nigeriens believe that *gurias* expand within a woman’s vagina, eventually resulting in a woman’s inability to engage in sexual intercourse by physically blocking the vaginal canal. The *wanzami*, the local surgeon/barber, must then cut large amounts of tissue off from the vagina, a procedure that is known to be dangerous and widely cited among rural Nigerien women as a potential cause of fistula. Women who develop fistula as a result of these local surgeries to address *guriya* are then

left with multiple problems, the problem they often cite as their “original problem” or “real problem” that may include the inability to menstruate (and thus conceive children) as well as the inability to consummate their marriages (and thus conceive children and please their husbands). As *guriya* hinders couples from engaging sexually with one another, it is often incredibly shameful for both the husband and wife. Husbands often feel ashamed, resentful, confused and angry at their wives’ inability to have sex or produce children and unsure what the problem is—some begin to wonder if their wives are actually women at all.

Both Sadiya and Zara’s stories highlight the importance in local understanding of healthy vaginas as places able to receive penises and deliver children, which, to a large degree, define womanhood locally. Indeed, both Sadiya and Zara—and in fact many women with fistula whose vaginas were “broken” or “unhealthy” due to their incontinence—were considered “almost men” or “men” due to their perceived pathological genitals.

For both Sadiya and Zara, the quest for normalcy continued after their fistulas were cured and their continence restored. In Zara’s case, when she tried to resume life with her second husband, she found it untenable. Unable to consummate her marriage, she found that her husband’s warmth, generosity, and patience waned (and her co-wives’ abuse, insults, and denigration waxed in turn).

The local notion of *guriya* highlights an important feature of fistula, that it can be both a cause and a consequence of other obstetrical and gynecological problems, specifically vaginal abnormalities or congenital malformations. Women I spoke with often complained that they had not seen their periods, that their vaginas were misshaped, that their uteruses had abnormalities, and when these problems resulted in women’s inability to engage sexually with their husbands, and thus to conceive children, these problems often caused more anguish and social devastation

to women than did their fistulas. Many women in my sample like Sadiya or Zara who had been healed of fistula continued to seek care due to residual concerns about their gynecological or sexual health. For many women, fistula treatment is not the end of road; rather, the restoration of continence is merely one step closer in their quest for normalcy—fistula a consequence of what these women sometimes call their “real” or “original” problem.

Even for the majority of women, whose fistula is the result of obstructed labor rather than local surgical remedies for *guriya*, fistula is often accompanied with other maternal morbidities (many of which, such as secondary infertility, can be more pressing or worrisome for women). Yet, it is fistula that has garnered attention, and thus donor dollars, while other maternal morbidities have not. So, while Western interest and attention often sets health agendas in the developing world funding specific illnesses and conditions while overlooking others, Sadiya and Zara’s stories illuminate the a larger field of gynecological and obstetrical health concerns which are often rendered invisible by the shadow of fistula.

Chapter 9

Child Bearing, Laboring, and Obstetric Catastrophe

9.1 Six Beds, Sixty Minutes: A Microcosm of Maternal Health in Niger

“Monday mornings are the worst,” the nurse told me as we waded through pools of women at the *Maternité Issaka Gazoby*, reminding me that just like traffic patterns, the hospital had its own rush hours. “Women wait at home all weekend, then come to the hospital after things have become urgent. You haven’t finished with one patient before three or four more urgent cases need your attention.” The nurse dressed me in an oversized white coat as we walked, the sartorial symbol that opens all doors here—a veritable *carte blanche*. She left me in the emergency triage and treatment room, where women from all over the region and the country were referred for a host of issues including eclampsia, advanced gynecological cancers, and myriad obstetric catastrophes.

The room was small, about the size of a large bedroom. There were six black plastic examination tables, filling the room until only one thin aisle was left vacant. In this small room, a single slice of the day, a single set of patients, one single hour, reflected the challenges practitioners face, the battles women fight, and the reality of maternal health in the Sahel.

I begin this chapter with six short vignettes from the *Maternité Issaka Gazoby*, the highest referral hospital for women’s gynecological and obstetrical care in Niger. I found myself at *Issaka Gazoby* looking for answers to the question ‘what went so wrong?’ because so many women with fistula in Niger found themselves at this center, the terminus of a catastrophic delivery gone awry. These short vignettes capture the physical pain, stoicism, shame, social

triage, obstacles to care, poverty, and quest for motherhood that will be explored more fully in this chapter and that undergird the experience of laboring and obstetric complications in Niger.

Bed 1: Suffering in Silence

At 9am, a woman arrived with a half-delivered baby. Her vagina had torn and the baby was stuck. After some expert navigation by the midwife, the baby was delivered, and despite having 12 toes, miraculously, he was alive. His mother, however, was worse for the wear. A midwife stitched up her deeply exposed flesh. The woman grimaced; she clenched her teeth. She feverishly massaged her abdomen each time the needle dove back into her skin. The midwife gave her nothing to dull the pain. “If she needs it, we will give her Tylenol after,” the midwife assured me as the needle burrowed deeper into the woman’s flesh. Blood trickled down her legs and pooled beneath her; the woman didn’t make a sound.

Bed 2: Transgression and Trickery

At 9:10am, a woman with a haggard red and black weave shuffled in. She made pained expressions. She groaned. She screeched. “She’s not Nigerien,” a midwife told me. “That’s why she’s crying, that’s why she’s making a scene. It’s shameful. Nigerien women aren’t like that. They are courageous.” The nurse was right—the woman, Grace, was from Togo and had moved to Niger to marry, but it had not gone well. Grace confided in me that she took medicines to abort. I wondered if the grimaces that painted her face, the moans that pursed her lips were born from pain—the physical consequences of a botched abortion in a place with no legal means for a woman to choose, or if they were performative, an attempt to conceal her transgression of the law. Grace asked me in a hoarse whisper, “They will take it out, won’t they?” She looked at me with pleading eyes, “I have two kids already, and there’s no money now for another. There

is just no money. I need work. They must take it out.” The emergency room filled up—in a room no bigger than a bedroom, two dozen people squeezed inside—the smell of sweat and blood and vomit and amniotic liquids mixed in the air, a vile potpourri. Grace quieted down, reanimating with dramatic displays of pain only when a nurse caught her eye.

Bed 3: The Invisible Crisis

Around 9:15 am, a girl was wheeled in, just referred from a rural health clinic. It was not clear if she was conscious. Her neck was limp and her head dangled off the back of the wheelchair. Suddenly, her head shot up as she vomited repeatedly down her front. She jerked and began to fall towards the tile below. My hand shot to her shoulder, but I struggled to keep her up. The midwife eyed me with an air of exasperation. “Let her fall,” she said to me. The woman tumbled to the floor, arms and legs akimbo in the middle of the room. Workers and patients and clinician stepped over her as eclamptic seizures gripped her body.

Bed 4: Who You Know

At 9:30 am, a young woman in a pretty dress with a plump face and a round belly pulled the attention of all the head nurses and the passing doctors. While other women were losing blood, losing consciousness, losing babies, I could not quite pinpoint what this woman was on the verge of losing—her urgency was not visible. She would get up every twenty minutes or so, and walk to one place or another, undergoing blood tests and ultrasounds. In her absence, women would slip onto her bed, hoping to be seen in the interim. The young woman sprawled on the floor from Bed 3 began to seize and I stepped backwards, bumping into an immaculately dressed *Hajiya* (an affluent woman who had made the pilgrimage to Mecca). After apologies

and introductions, it turned out that she was the former director of the hospital. The woman in bed four? Her daughter.

Bed 5: The Malady That Must Not Be Named

At 9:45am, an older woman contorted her face in pain as she slowly, with careful attention, removed her blouse. While her left breast hung low—a flat and flaccid marker of her reproductively fruitful years of yore—her other breast was hard and high, like an artificial and over-sized breast, except blooming with red and white sores, puss, and exposed tissue. This was breast cancer in the Global South, where cancer is a taboo and undocumented illness. “It is a Neuro,” the doctor told her. She did not know that a neuroblastoma was a malignant cancerous tumor, but that was the point. “Sometimes,” her doctor told me, “I tell them it is a tumor. But we never use the word cancer here.” Cancer is thought of as a death sentence. Patients lose hope, he explained. Just from a quick glance, the doctor knew that the cancer has metastasized. With few words, he left her alone on the plastic black table, struggling to dress herself.

Bed 6: The Lives That Count

At 10 am, a thin woman curled up on the floor, next to her was a shadow of a baby—a skeletal thing that came in to the world months too soon. The mother was severely anemic and could not produce any milk. For four days, this two-pound outline of a human had not had a drop to drink or eat. She was quiet, there was no elasticity to her skin, and through her nearly transparent skin, each rib was visible. “Can’t we do anything for this baby?” I asked the nurse. “Is there no artificial formula for babies like this?” “Why?” the nurse asked me in response, “The mother isn’t well. What happens if the child lives and the mother dies? And even if she the mother lives, so you feed the baby today. Look at that woman; she can’t afford formula.

What happens when you are gone? Who will feed the baby then?” the nurse said to me indignantly. In Niger, child mortality is high. When babies die, parents mumble: God didn’t intend for this baby to continue on earth. It wasn’t its time. It wasn’t God’s destiny. As this woman held the fragile being, shaking her a little too hard, holding her a little too far, I wondered if this mother had already resigned this life to “destiny.”

* * *

Of the nearly half-million maternal deaths per year, 99% are from resource poor countries, and over half in sub-Saharan Africa. In the United States the maternal mortality ratio, known as the MMR,⁷⁸ is 28 deaths per 100,000 live births, as compared to the worldwide MMR of 210 deaths per 100,000 live births, and the sub-Saharan African MMR of 500 deaths per 100,000 live births (World Bank 2014). In Niger, women fare even worse. The maternal mortality ratio in Niger is 630 deaths per 100,000 live births, and the lifetime risk is 5%, meaning that 1 in 20 Nigerien women will eventually die from pregnancy related complications (World Bank 2014).⁷⁹

Interventions into childbirth and mothering have a long history in West Africa (Hunt 1999) and continue to be consistently among the top priorities of most international aid organizations in Niger. However, MMRs and lifetime risk estimations do not reveal anything about the felt experience of birthing in the country dubbed by the global media as the “worst place in the world to be a mother” (BBC 2012). In this chapter I explore birthing in Niger—how womanhood is achieved through the idealized birth in which pain is endured through stoicism

⁷⁸ The MMR is defined as the number of women who die from pregnancy-related causes while pregnant or within 42 days of pregnancy termination per 100,000 live births.

⁷⁹ Lifetime risk of maternal death is the probability that a fifteen-year-old female will die eventually from a maternal cause assuming that current levels of fertility and mortality (including maternal mortality) do not change in the future, taking into account competing causes of death. Niger has the third highest lifetime risk, following Chad and Somalia (World Bank 2014).

and solitary birth, the social and emotional costs of childlessness, the role of the local midwife, how birthing complications are managed locally and in health clinics, and how the poor quality of biomedical care women frequently receive during obstetric complications leads to heightened perceptions of iatrogenic fistula.

I use the popular public health phase-delay approach to maternal mortality and morbidity to examine the causes of fistula among the women in my research sample. Ultimately, I argue that global health campaigns place too much emphasis on cultural and individual access barriers rather than structural impediments to *quality* health care. Through ethnographic narrative I argue that women with fistula did access biomedical care, however, the quality of care was exceptionally poor as women frequently experienced broken referral chains, the refusal of care, poor-quality care, and inappropriate interventions.

9.2 Failed Womanhood: Childlessness and Infertility

In Niger (as is the case with many places across the globe), children are conceptualized as a source of wealth. Because adulthood and individual value is so strongly linked to reproductive successes, childless women in Niger suffer social marginalization and infertility-stigma. Indeed, Nigerien women are defined largely by their reproductive role, and are not even considered fully adult until they have children.

In fact, some women with fistula I spoke with claimed that their fistulas posed fewer social problems than did their lack of living children. Fasuma, a twenty-three-year-old Fulani woman in my sample who had four previous pregnancies but no living children, explained:

For a woman who is married, she has value and is more at ease with her sickness than those women who aren't married... because she has children, and children are so valuable... Those who have children, her husband can stay with her because of their kids. He will be patient, even if she's sick. But, those who have no children, even if she has a husband, he will think about taking a second wife.

As Fasuma and I discussed in greater detail the importance of children, she noted the differential social treatment experienced by childless women—a social invisibility and discreditation that leaves childless women unmoored in social space:

For example, let's say that you and I are together and you have a child but I do not, when we go out together, it is you that people will welcome first because they will want to hold the baby and kiss the baby, but me, they won't even look at me. Life is different for women with children.

Fasuma recalled an experience from the previous year that confirmed her feelings of valuelessness due to her inability to bear living children:

One day some friends of mine and I accompanied our friend, a young bride, to her new husband's house. One of the girls among us was married and had a young child. Night came, and we were to sleep there. There were so many mosquitoes in this village, but there were no mosquito nets. A man, a neighbor, had a mosquito net. He gave his mosquito net to our friend when he saw that she had a baby. He said it was thanks to the baby that she got it. The rest of us suffered during the night. There is a real difference if you have a child. People treat you differently. They value you more. You have more value.

Fasuma then looked straight at me, and as if calling me on a bluff, she reproached me: “Even for you, the situation is the same. You come each day, and you greet all of the women, but those who have babies, you sit with them, you kiss the babies and you put them on your back. You pass more time with the mothers. Even for you, it is the same.”

Not only did childlessness negatively impact women's conception of self and understanding of their place within their social networks, but many women also attributed divorce following fistula not to the illnesses itself, but to the implications the illness had on their future fertility. Binta, a twenty-six-year-old Hausa woman with three pregnancies and no living children, explained that childless women are ridiculed and vulnerable to divorce or marital mistreatment as husbands will be affected by community members' gossip: “People will say, ‘she only eats and shits, what's her use?’”

Along with the social costs of infertility, childless women often suffered a high emotional cost as the inability to bear living children caused extreme anxiety about the future, sadness, personal devaluation, and the loss of identity as an adult woman. Hagera, an eighteen-year-old Zarma woman with no living children, explained that she was a “waste of life” because she had no children, “you can’t be a woman when you aren’t married and you can’t stay married without having children. It is only young girls that aren’t married and have no children. Not adult women.” Raha, a fifty-five-year-old Hausa woman with twelve previous pregnancies and no living children, explained that, “One of my sisters says that I am not even a woman because I don’t have a single child. I think she is right.”

It was not only women who suffered from infertility who felt the social and emotional burden of constricted fertility. Women with few children to some extent also shouldered this burden. Salamatou, a twenty-eight-year-old Hausa woman whose uterus had been removed during the labor that caused her fistula, could not bear additional children. She attributed both her social and emotional troubles on her limited fertility:

Women with fistula always have worries. They see other women living with their families, their children, but she is alone. My problem is that I only have one child. I believe that if I had more children, my husband would not have left me. He would have asked himself, “but who will take care of these children?” So he’d be obligated to stay with me. But, I only have one child and now I cannot have more. So, he left me.

When Nigerien women were asked in a national survey how many children they would have if they could plan their ideal family, women reported an ideal fertility rate of 9.2 living children, increasing to 9.6 among rural women (DHS 2012). For women like Salamatou who are left with only one child, small family size is socially aberrant and personally disappointing.

High Rates of Stillborns Among Women With Fistula

Although many women with fistula had moderately high levels of pregnancy (averaging 3.7, ranging from 0-12), women averaged only 1.1 living children each (ranging from 0-6) (see Figures 3.2 and 3.3). Indeed, women with fistula in my sample reported higher rates of child mortality than the national average, which is estimated at 127 children out of 1,000—meaning that 12% (just over one out of ten) of children in Niger will die before reaching the age of five (DHS 2012). For rural populations, however, child mortality rates in Niger are worse—163 of 1,000 (or 16.3%) (2012), dropping from a high of 35% in 1992 (and steadily declining to 33% in 1995 to 23% in 2006) (DHS 1992; 1998; 2006; 2012).

Women with fistula have particularly few living children compared to the number of pregnancies they have carried to term. The percentage of child loss is disturbingly high among women in my sample—averaging 76% (meaning that just over three children out of every four pregnancies die). The percentage was highest for women with only one pregnancy, at 91% (meaning that nine out of ten babies from first pregnancies die), and lowest for women who had between 6 pregnancies (52%) (see Figure 9.1). These data revealed that women with fistula have particularly low survivorship for full-term pregnancies that come to parturition. Based on my interviews, the majority of these deaths happen during labor and infancy.

In order to obtain more comparable data, I calculated mortality percentages excluding stillbirths (as international organizations such as DHS do not include stillbirths in child mortality rates). I found that stillbirths accounted for a vast majority of mortality percentages in my sample, decreasing the average mortality percentage from 76% to 13%, and, in fact, resulting in a mortality percentage that is lower than the national average for rural populations. However, these data may be misleading. See for example the women who had one pregnancy. When

stillbirths are included in the calculation, the mortality percentage is over 91%; yet it drops to 3% when stillbirths are not included, thus rendering the loss of that child invisible.

These data demonstrate that women with fistula have no harder time than their Nigerian counterparts keeping their children alive once a healthy child is born, but have a tremendously difficult time birthing live children. Although clinical evidence is scant for the high incidence of stillbirths among women with fistula in my sample, physicians I spoke with offered two hypotheses. First, these women may be particularly vulnerable to vaginal and uterine infections during pregnancy due to their fistulas and other gynecological damage. Second is that whatever was resulting in obstetric complications during the labor that caused fistula (cephalo-pelvic disproportion, for example) continued to cause problems during prior and/or subsequent labors.⁸⁰

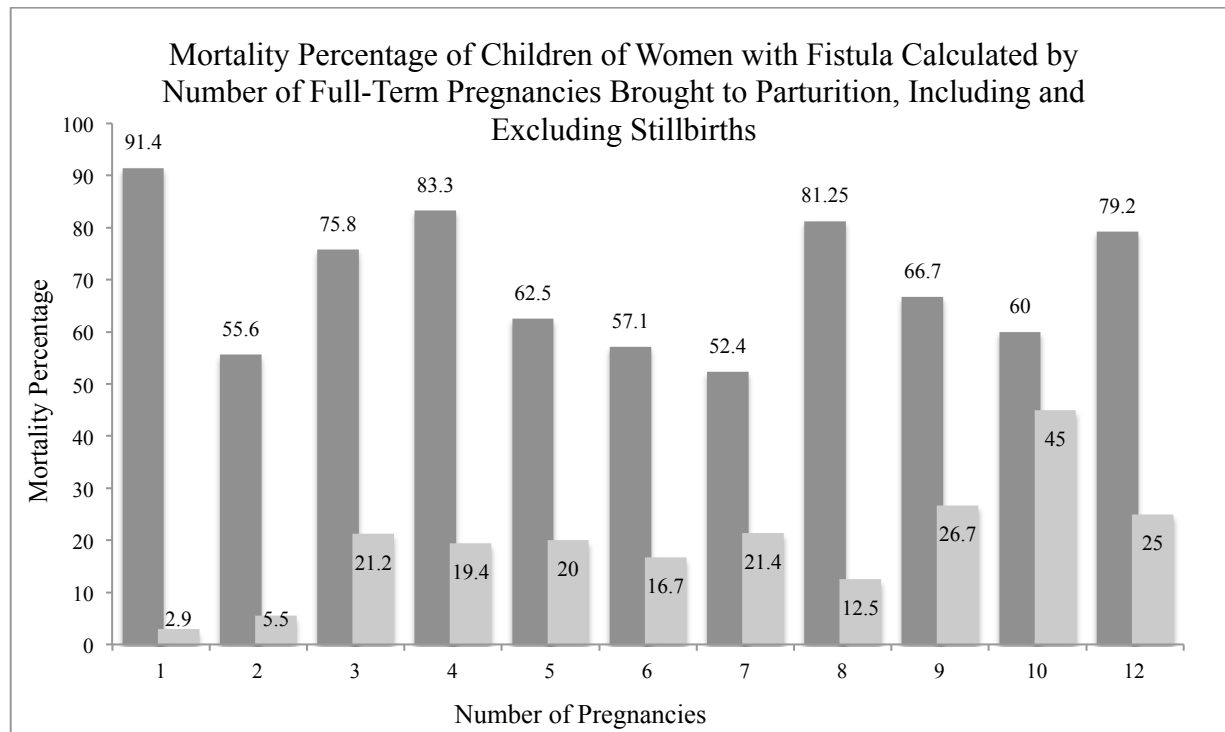


Figure 9.1: Mortality percentage of children of 98 women with fistula calculated by the number of living children divided by the number of full-term pregnancies (not including first and second term spontaneous abortions). In dark grey are the calculations for mortality percentages including stillbirths, and in light grey are mortality percentages not including stillbirths. The average total mortality percentage is 75.9%, and the average mortality percentage when stillbirths are excluded is 13.1%.

⁸⁰ Considering the magnitude of the problem of stillbirths among women in my sample, these data suggest that more research on the causal relationships is urgently needed.

In Hausa, the word *wabi* is used to denote a woman whose children all die. As women with fistula tended to experience higher than average percentages of child mortality, women with fistula were often quite familiar with the pejorative term. Maou, a fifty-year-old Hausa woman with nine previous pregnancies and only one living child explained that despite having a child, people call her a *wabi*. “They even call trees whose fruits fall to the ground before they are mature *wabi*. And me too, they call me *wabi* because my fruit also falls before it is ripe,” she explained. Baraka, a forty-year-old Tuareg woman with eight pregnancies and no living children, explained that although no one treated her poorly because of fistula, she was mistreated because of her failed fertility: “Some people would say ‘You there! You don’t even have children. You just give birth to dead kids. Get out of here!’”

The social and emotional pain of childlessness, and thus failed motherhood (and in turn, failed womanhood), was particularly acute for women with fistula who suffered from markedly high percentages of stillborn children. These women dealt with twin crises of incontinence and illness management and repeated traumas of infant death during birthing, leading to social alimination, increased vulnerability to divorce, and internalized identity loss.

9.3 The Idealized Birth: Patience, Courage, and the Mastery of Pain

Women in Niger are expected to birth both alone and silently. Birthing is an opportunity for women to demonstrate their courage and patience through the mastery of pain and suffering. Although women recognize that the “ideal” birth cannot always be achieved,⁸¹ the preference to birth alone is tied not only to a desire to demonstrate courage, strength, stoicism, and patience in

⁸¹ Women typically do not birth alone during their first births or if they have a history of birthing complications. Other categories of women locally perceived as “high risk” may also be advised not to birth alone such as women who have birthed many children, or women who are considered ill or weak, for example.

an effort to achieve an idealized womanhood, but to avoid the social repercussions of a poorly performed labor.

Women regularly noted that birthing was a woman's only opportunity to demonstrate that her strength and fortitude equaled that of her husband. Mirroring similar parables and proverbs related to birthing throughout West Africa, many women explained to me that the ideal birth is one in which a woman feels the beginning of her labor, finishes her household chores without telling anyone of her condition before retiring to her room to silently and solitarily birth her child, only alerting her family of the child's arrival through his or her first cries. Twenty-six-year-old Binta explained:

When you give birth, even if we are in the same house, no one should know. If you are preparing food in your household and labor comes, you should quietly enter into your room. They should only know that you've given birth when the baby cries. If God gives you the chance to be pregnant, giving birth isn't hard. God facilitates it. During my labor, I was pounding millet when I felt the labor start. I finished this work then I went into my room and began to deliver. Only when the baby was out, once he was in my arms, did I call the others.

Although birthing norms are rapidly shifting due to increased national and international efforts to move birthing into clinics, over 70% of births in Niger still take place at home (DHS 2012), and approximately 20% of births are completely unattended (see Table 9.1 and Table 9.3).⁸² Compared the sub-Saharan countries that neighbor Niger where rates of birthing alone among rural populations hover between 1-6% (with the exception of Nigeria) (see Table 9.2), across ethnic lines, Nigerien women are distinctive in their cultural ethos of the idealized lone birth.

⁸² Due to increased focus on interventions aimed to promote birthing in health clinics (such as the reduction or elimination of user fees for most maternal health services), there has been a dramatic increase in the utilization of health centers, evidenced by the jump from 8% of births in health centers to 21% in just six years (See Table 9.1, DHS 2006, 2012).

Assistance During Delivery of Rural Women in Niger Using All Available DHS Data							
	Doctor	Nurse/ Midwife	Trained Traditional Birth Attendant	Nursing team	<i>Ungozoma</i>	Family/ Other	No one
2012	0.5	20.7	----	---	36.3	25.8	16.8
2006	0.2	8.1	16.7	24.9	54.9	1.0	19.2
1998	0.2	7.9	29.6	37.7	38.4	15.6	8.2
1992	0.3	4.6	20.0	4.9	29.4	25.8	19.9

Table 9.1: This Table highlights the percent distribution of live births in the five years preceding the surveys by person providing assistance during delivery of rural women in Niger for all available Demographic and Health Survey Reports (1992—2012). Over the years, categories have shifted, making direct comparison difficult. However, of note is that there has been little change in the percentage of rural births assisted by doctors and unassisted births consistently hover just below 20%.

Assistance During Delivery of Rural Women in Niger and its Neighboring SSA Countries Using Most Recent DHS Data							
		Doctor	Nurse/ Midwife	Trained traditional birth attendant	Traditional birth attendant	Family	No one
Niger	2012	0.5	20.7	--	36.3	25.8	16.8
Mali	2012 -2013	2.1	26.7	21.9	32.3	10.2	6.9
Burkina Faso	2010	0.2	15.0	46.5	17.4	18.7	1.6
Benin	2011- 2012	4.2	75.0	1.0	6.1	12.1	1.2
Nigeria	2013	5.5	15.2	1.2	27.5	28.2	17.0
Cameroon	2011	5.3	41.4	--	13.2	34.6	4.5
Chad	2004	0.3	5.7	18.2	30.9	52.8	4.2

Table 9.2: This Table highlights the percent distribution of live births in the five years preceding the surveys by person providing assistance during delivery of rural women in Niger and Niger’s neighboring countries during the most recent Demographic and Health Survey Reports for each country. The table highlights Niger’s high rate of unassisted births, matched only by Nigeria. Interestingly Nigeria has vast regional difference in birthing alone—in the South West region only 1.3% of women birth alone, compared to the North West zone (which is primarily the Hausa ethnic group, like Niger), where 27.8% of women birth alone (DHS Nigeria 2013).

Nearly every woman I spoke with on the subject (regardless of age or ethnicity) explained that showing too much distress during labor (particularly evidenced by verbal or physical signs of pain such as crying or flailing) brings a woman (and to some extent, through an unspoken transitive property, her family) shame. Forty-five-year-old Habsu explained, “If you cry, or let the pain get to you (*jin zahi*, literally, feel heat) you will feel nothing but shame after.”

To avoid shame, insults, or community gossip, laboring women must carefully avoid complaining, being “alarmists,” talking too much, excessive movement, screaming, kicking, flailing, or any visual or audible cues of suffering or struggling. Because such mastery of one’s body in the face of such extreme pain is so difficult, many women prefer to birth alone, free from

the gaze of onlookers, where a grunt or whimper, a tear or flail will be unremarked by anyone, and thus have no social consequences. Women regularly expressed a deep fear of gossip and mistrust in neighbors that word could get out that women did not master their pain during labor.

Labors that deviate from the ideal homebirth are often shrouded in shame and women's feelings of inadequacy as a woman and wife. Unsurprisingly, this stoic take on labor has important consequences for obstetrical complications, often delaying women's decisions to seek care, and causing additional anguish and shame when a labor fails to progress normally.

The Role of the *Ungozoma*, or, Midwife

I visited Chima, a seventy-year-old Hausa *ungozoma* (local midwife) in her home located in a small village outside of Maradi. I sat on small wooden stools with Chima and her co-wife, a wizened old griot whose last tooth wobbled as she belted out impromptu songs praising Chima's craft. Chima became an *ungozoma* fifteen or twenty years prior because her paternal aunt had practiced as an *ungozoma* and trained her. When I asked Chima to describe her work to me. She ducked into a small, mud, circular structure, returning a minute later with a rusted tin box, with the barely visible UNICEF logo emblazoned on the lid. She opened up her workbox and took out a razor, a spool of string, a long plastic apron, a pair of old rubber gloves, a bar of soap, a vile of perfume, and a silver bowl, arranging the items carefully between us.

Unlike many places in sub-Saharan Africa where midwives have and still do play an important role in assisting women with birth and recognizing (and referring) emergencies, in Niger, because women are encouraged to birth alone without assistance, local midwives do not typically assist in deliveries. Rather, the expertise of a local midwife is called upon after the child has been born. Older, multiparous Hausa women may become an *ungozoma*, or midwife. Hausa midwives typically are not biomedically trained and have few medical resources and little

knowledge of how to deal with complicated pregnancies (Wall 1998). Rather, *ungozoma* serve as ritual officiates of pregnancy and childbirth, administering ritual baths following delivery, caring for and inspecting the new child, and properly attending to the powerful placenta.

Most women I spoke with explained that *ungozoma* “don’t do anything” until after the labor has finished, at which point they cut the cord, take care of the baby, take care of the placenta, care for the woman, and clean away the blood. If an *ungozoma* is called during a labor, she typically will not use any physical interventions (rarely even touching a woman). Rather, she is expected to be trained in the Quran and capable of reciting prayers of protection. An *ungozoma*’s service might continue throughout the forty-day post-partum period when she may come every day to a woman’s house to prepare hot water infused with special herbs for the woman to bathe in and serve the woman a medicinal porridge to fortify her body and protect her.

Chima (the *ungozoma* I spoke with) explained to me that once a woman has already birthed, an *ungozoma* is called to cut the umbilical cord. First, Chima performs what she believes to be her most important intervention, prayer. Chima recites several Suras from the Quran that she believes will protect the mother and child. Then, with a razor, she separates the baby from the mother, and ties a string tightly around the cord to stop the bleeding. Next, Chima sets the baby aside and attends to the placenta. “If the baby is a girl, I wash the placenta four times. If it is a boy, I wash the placenta three times,” she explained. Chima speculated, “Maybe women have more experience than men, maybe when a girl is born there is more to wash away.” Chima buries the placenta in the courtyard of the birthing woman’s house, next to the shower, “God gives the placenta. It is part of the child and it must be protected, it cannot just be thrown out.” For many women in Niger, the placenta holds mystical powers, and is treated with special

care. If proper placenta rituals are not followed, many Nigeriens believe that women can suffer from spiritual consequences and infertility:

Women suffer if you throw the placenta on the ground. The placenta knows that you didn't take care of it, so the next time, it will stay inside the body, it will refuse to come out. You will have to go to the hospital to get it cut out. It is angry because you love your child, you take care of your child, but the placenta, who took care of your child for nine months, you just threw out. You showed it no gratitude so it will punish you.

Notwithstanding the skill required to attend to the placenta, Chima explained that the most important requirement of an *ungozoma* is her discretion:

You must be able to keep a secret. You can't tell people if a woman cried out. People would say 'you there who cried during labor, don't you feel shame'... Since the time of our ancestors, we don't cry during labor. If a woman cries, it means that she doesn't have strength—that she can't support the suffering that life brings. That is shameful.

Despite Chima's dedication to discretion, not all women had confidence in an *ungozoma*'s ability or willingness to keep her client's birthing behavior secret. If a woman could not birth completely alone, perhaps because it was her first birth or because she had a history of birthing complications, some women preferred to rely on a close friend or family member who, because of complex webs of social entanglements, might be a more reliable confidant. For example, thirty-six-year-old Dije explained:

The women in my village do not call the *ungozoma* during labor, only after. If she comes during, she might tell all of your secrets. If you cry, she will go and tell everyone. It is better that an older family member is present, because while the *ungozoma* will tell everything, your mother's sister won't say a word.

Because of the importance placed on embodying womanhood through the mastery of pain and stoicism, birthing alone is idealized in Niger, but when birthing alone is not possible, an older family member such as an aunt or close family friend is often (but not always) preferred to an *ungozoma* due to the midwife's limited skill-set and the concern over her discretion. When women fail to delivery quickly, they may call an older female relative or a midwife to intervene.

Some women recounted strategies commonly deployed that require physical touch, the most popular of which including gentle stomach massages to “wake up” the baby and encourage its descent, and the attachment of fabric tightly around a woman’s torso, between her breasts and belly button, to stop the child from ascending. However, many women were adamant that *ungozoma* or other local birth attendants do not typically touch laboring women, employing instead strategies that rely on prayer, superstition, herbal remedies, and occult forces. Nearly all women I spoke with used amulets, prayer water, and (to a lesser extent) herbal tisanes to encourage the healthy progression of a birth.

Amulets, commonly constructed of written prayers encased in darkened leather, hang visibly from the necks, arms, hair, legs, or bellies of young children across Niger. Less visible are the amulets adults attach to themselves. Stowed in pockets or hidden underneath clothing, many women rely on the protective powers of amulets. During labor, amulets are commonly used to encourage the safe passage of a child, particularly in the face of obstetric complications. When a woman’s labor fails to normally progress, her first recourse is often to call an *ungozoma* or female relative who attaches amulets to her body. Some women explain that an amulet may be dropped into a calabash of water that is then drunk by the laboring woman. When the water (thought to be infused with the power of the amulet) is drunk, the woman drops the calabash and amulet on the floor, a gesture that is thought to catalyze contractions and successful delivery.

Other practices include the active ingestion of prayers. This is done several ways. First (and most commonly), known as *rubutu*, a religious leader is asked to write a prayer with chalk on a child’s handheld black board (or sometimes just on a scrap of paper). Water is then poured over the writing, washing away the prayer. The water (now thought to be infused with the powerful prayer) is given to the woman to drink (this practice is also common among the Hausa

of northern Nigeria, see Murphy and Baba [1981]). Alternatively, an *ungozoma* or older respected woman will fill a cup with water, then cover the opening with her mouth, whispering the prayer into the water until it had been infused. The water is then given to the birthing woman. Or, an *ungozoma* might whisper a prayer into her cupped hands, then swiftly transfer the prayer onto the woman's stomach. Typically, it is only after a combination of these strategies has been deployed without success that a woman's family will begin the search for biomedical care.

9.4 Understanding Maternal Morbidities

Despite high rates of maternal mortality, for every woman who dies from obstetric complications, as many as 40 more survive with chronic disabilities, while up to 60 more sustain a variety of physical, social, and psychological consequences (Filippi et al. 2006; Alio et al. 2010). According to most estimates, 15% of pregnant women will develop complications during pregnancy or delivery (Essien 1997), and when these complications are not expeditiously treated by trained practitioners, women are at risk for morbidities such as obstetric fistula. These complications may be categorized on a continuum, covering a range of consequences from damage to pelvic structures, to infertility, to the most severe, so called "near-miss" events (where women 'nearly missed' maternal death). Annually, 1.4 million women suffer from near-miss events (Filippi et al. 2006), experienced by 3% to 9% of women in developing countries, (as compared to less than 1% of women in the United States), most of whom sustain some form of chronic injury or disability (Wilson and Salihu 2007).

Developed within the school of public health by Sreen Thaddeus and Deborah Maine in 1994, the three-phases of delay model differentiate and categorize the types of barriers responsible for belated treatment and resulting poor outcomes of obstetric complications: (1)

delay in deciding to seek care after the onset of complications, (2) delay in reaching a healthcare facility once the decision to seek care has been made, and (3) delay in receiving medical care once the facility has been reached. First phase delays (prolonged laboring at home) often result from a complex synergy between distance, cost, quality of health care, and subjective experience, perception, and expectation synthesized within a broader context of gender, household decision making processes, and socioeconomic and educational status. Second phase delays (prolonged laboring on the road) address the physical barriers to reaching health care facilities, including transportation, cost, and facility distribution. Finally, third phase delays (prolonged laboring at healthcare facilities) are the result of inadequate healthcare systems lacking in skilled staff, supplies, medications, and organizational efficiency, or practitioner bias based on patients' (perceived) wealth, ethnicity, or social status.

Many women in my sample experienced all three phases of delay. The story of twenty-year-old Hauwa illustrates this. She resisted her marriage to a maternal cousin, fleeing from her new husband often, and fighting with him mercilessly. Their relationship remained acrimonious for years, and when the contractions of Hauwa's first labor began, her husband punished Hauwa by hiding her cell phone, forbidding her from calling her grandmother for help, "He said that I didn't need help, he said I could be strong and courageous and birth alone." Hauwa birthed alone for three days, "During these three days, I knew that there was a problem. For three days I couldn't walk around, I couldn't urinate. I knew that I was broken." On the night following her third day of labor, Hauwa left her house while her husband slept and called her grandmother for help, "[My grandmother] said that my husband wanted me to die, that's why he didn't bring me to the hospital." Here, Hauwa experienced a first phase delay, or, prolonged labor at home.

By the time her grandmother made the long journey to Hauwa, the child's head was born, but the rest of his then blue body was still stuck inside of her. The nurse at the local health center took one look at Hauwa, and shook his head—there was nothing he could do for her. Hauwa's grandmother hired a mule cart to take them to the nearest hospital. The trip took nearly eighteen hours. Now, Hauwa experienced a second phase delay, or, prolonged labor on the road.

When they arrived at the health center, Hauwa's grandmother began to hear rumors about the hospital's doctor:

There was a man who operated on women there, when he performed surgeries, he would also profit by taking out organs from the women to sell. The women told us that if he operated on me, I would die. They said that just that day there were two women who died because of him. So my grandmother refused to let him operate on me.

Hauwa believed that the staff were angry with Hauwa for refusing care and thus punished her, letting Hauwa sit a full day and night without any intervention. Finally, the long-since dead child was removed with forceps. The next day, Hauwa asked her grandmother “women that give birth, does their urine run like this?” lifting her wrapper to show her grandmother the urine that pooled between her legs. “The nurses said that they didn't know what I had. They sent me home, and it wasn't until the next year that we heard of fistula.” Finally, in the practitioner's refusal of care, Hauwa experienced a third phase delay, or, prolonged labor at a health care facility.

First Phase Delays: Prolonged Laboring at Home

In the context of fistula prevention and eradication efforts, a large focus has been placed on reducing what has been called first phase delays, or prolonged laboring at home, the reasons behind such delays are presumed to be primarily “cultural.” The assumption is that because of familial negligence, “traditions,” or “ignorance” women wait too long at home before seeking emergency obstetric care. These women are thought to not seek health services until the

physiological damage has already been done. As a result, fistula prevention efforts often discourage home births, encourage pre-natal care (to familiarize women with health care systems and thus increase the chances that they would use health services during delivery), and focus on persuading husbands, parents, and in-laws of the importance of rapidly seeking care for a woman when her labor exceeds one to two days (see Figure 9.2).



Figure 9.2: Educational materials painted on cloth in French and Hausa used to educate rural villagers in Niger about obstetric fistula prevention, aimed at addressing first phase delays. (from top left to right). “It is important to go to prenatal consultations,” “It is important to obtain the permission of the mother, the husband, or the mother-in-law before evacuating a woman,” “Fistula comes from a labor that lasts two sunsets or more.”

In discussing the birth that caused fistula, many women did report prolonged labor at home. Of the women in my sample, women delivered an average of 1.8 days, or 43 hours (and ranging from 1 hour to 7 days), at home before seeking care (see Figure 9.3). It is important to note that only 12 women did not seek care at a health center at any point during their labor.

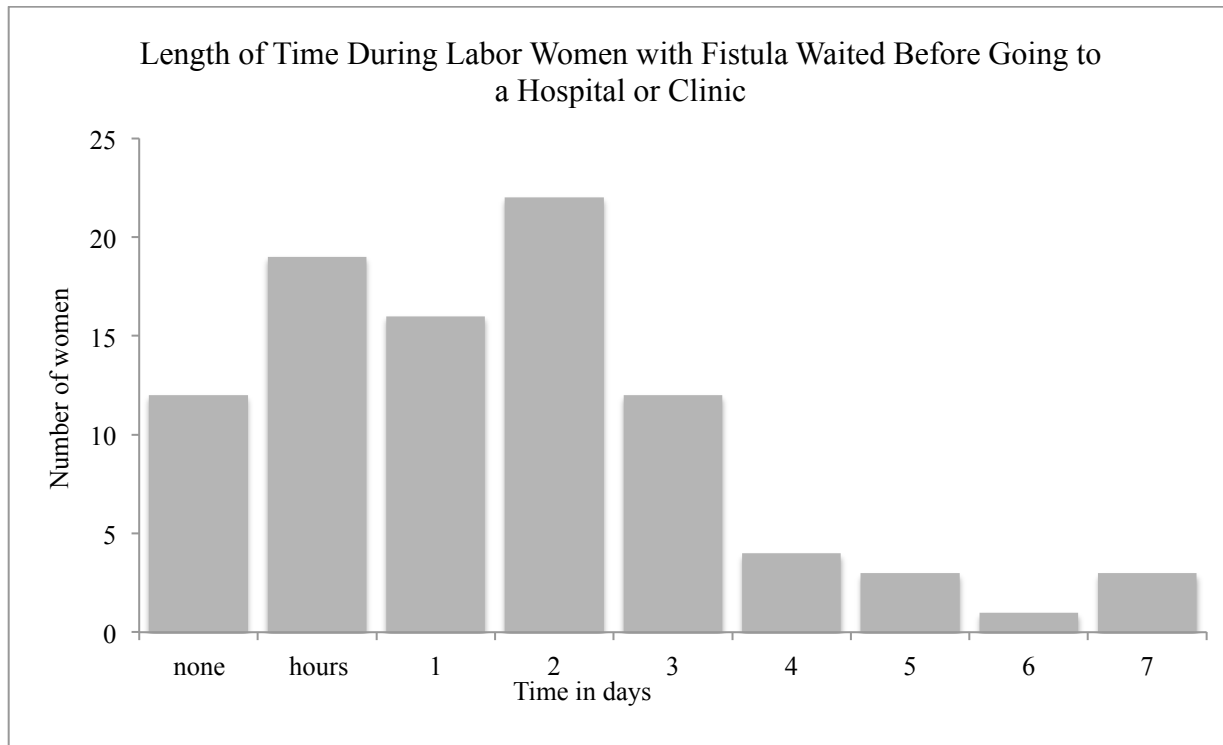


Figure 9.3: The length of time during labor that 92 women waited before going to a hospital or clinic for the labor that resulted in the development of their fistulas. For the 12 women who never went to a clinic, their entire length of labor is included.

However, protracted labors at home were not simply due to familial negligence or “tradition,” nor could they be attributed to ignorance. Rather, for many women I met, delays in evacuating women from homes to health centers were due to myriad factors, roughly divided into political, economic, cultural, and practical concerns.

Political concerns revolved around political instability and compromised safety that rendered travel to health centers unsafe (particularly true for women in northern Nigeria due to the tumult caused by Boko Haram). Aishatou, a twenty-five-year-old Hausa woman who had been living in northern Nigeria, labored at home for four days before seeking care at a health clinic. When I asked Aishatou why she waited so long at home, at first she explained, “It is the Tuareg tradition to stay at home and labor,” but then added, “It was a period with a lot of political activity—campaigning and propaganda—so the roads were very busy and not very

safe.” Aishatou, whose husband had been murdered just two months before her delivery by men affiliated with Boko Haram, tried not to leave the house during her pregnancy and feared traveling during her labor as well, which she judged more unsafe than delivering at home.

Economic concerns involved the high cost of hospital or clinic births (including transportation, medicine, and the opportunity costs to those who would accompany the delivering woman who could then not tend to responsibilities at home). Rabi, a forty-year-old Hausa woman, was in labor for four days at home before deciding to seek care at a clinic. She explained that, “To give birth in a hospital finishes all of your money” (*Haifuwa asibiti, kashin kudi ne*). People in her village, particularly old women who often attended births, advised her and her mother to wait before going to the clinic, knowing that a hospital delivery was expensive and potentially avoidable. So, “We waited to see if I could do it on my own.” Eventually, Rabi and her mother decided to travel to a hospital; however, they did not go to the closest clinic (which was missionary-run and charged for deliveries and the hospital bed), rather, they traveled over 100 additional miles to Sokoto, Nigeria where they knew that a hospital delivery was free.

Concerns which are classified as cultural,⁸³ include the reliance on and belief in the efficacy of local methods (such as herbs, prayer, or local midwives), lack of decision making power or autonomy of the laboring woman, and the shame both in birthing at a hospital and the inability to birth alone and unassisted. For example, Aissa, a twenty-six-year-old Kanuri woman who had fled from her husband, was in labor for two days before heading to a health center. When I asked her why she waited so long at home, she explained, “I couldn’t go by myself—I couldn’t decide by myself to go. I had to be brought. It was up to the family to decide when it was time to go. I had been chased away from everywhere, so I had to listen to my aunt. I didn’t

⁸³ I am reluctant to define this category as “cultural” as it suggests a naturalized, monolithic entity of “Nigerien culture,” overlooking the vast diversity, dynamism, and heterogeneity that exists within Niger. I use “cultural” to note locally held meanings and values, which while not homogeneous, can influence health-seeking behaviors.

have options.” Others, like Safia, a twenty-seven-year-old Kanuri woman and Hassi, a twenty-two-year-old Fulani woman simply explained, “I didn’t go because my parents decided I should stay,” and “My mom didn’t bring me.”

Young primiparous women in Niger lack the autonomy within the household and the perceived experience to decide when to seek biomedical care for birthing complications and thus must rely on more senior female members of their household. However, due to the shame that surrounds sex and birth, and the heightened shame when women are unable to achieve idealized birth and thus must access biomedical intervention, women (both young and old) are reluctant to voice concern about their births when they suspect problems.

Practical concerns involve the time needed to prepare (money, food, bags etc.) for the long journey to a health facility, the wait for accompaniment (when family members or husband have traveled or were gone for the day at markets or in their fields), the suspicion and mistrust in biomedical health facilities, and the assumption that the birth would progress normally (particularly salient for women who had a history of many unproblematic home births). Gomma, a thirty-year-old Hausa woman, waited a full day at home before heading to the health clinic because she and her family had to “prepare ourselves and find the money to go.” Naio, a twenty-nine-year-old Zarma woman who had given birth five times previously without any complications, was told by a nurse during pre-natal screenings that she had a high-risk pregnancy and needed to birth in a clinic. Still, she spent over three days at home before going to a clinic. She explained that, “For each time, when the labor began, it always started with a stomach ache—then the child would move. But it started with the liquid running and I wasn’t used to seeing this so I didn’t really know what it was or what to do. I thought that [the labor] would

progress normally, and that I wouldn't need to go to the health center." When Naio made the decision to go to the health center on the second morning of her labor, no one else was at home:

Some were in the field, and others were at the market. I sent a child to get my husband from the field, but mom was far from home because it was a market day. I went to the nearest health center alone, but when the nurse told me to go to [neighboring town with a larger health center], I decided to wait until my mom returned so she could accompany me.

Delays were explained by a combination of uncertainty as to when labor had begun, compounded by delays in preparing for the journey and waiting for accompaniment.

Second Phase Delays: Prolonged Laboring on the Road

Within public health, the term second phase delays refer to delays in reaching a healthcare facility once the decision to seek care has been made. Second phase delays may also reinforce first phase delays because lack of transportation, poor roads, and prohibitively expensive evacuation affect families' calculus regarding the decision to seek care. When health facilities are far away, or inaccessible because of poor roads, transportation, or expense, women and their families often wait until a concern has become a crisis before deciding to seek care. Second phase delays are thought to be such an important factor in the development of fistula that the Hamlin concludes that "fistula is the result of obstructed labor and obstructed transport" (Hamlin 2004).

Although second phase delays were not as significant as first or third phase delays in Niger, women in my sample did express concerns regarding the cost of, access to, and safety of transportation as well as the distance from health centers. Saouda, a thirty-year-old Zarma woman who was in labor for three days, explained that only on market days (held once a week) were there ever any cars in her village. So, when she experienced complications in her delivery, her husband hired a mule-cart to take her on the several hour journey to the nearest health center.

Because of the pain, Saouda fell off the cart onto the road twice. When she could no longer continue in the mule cart, she and her husband waited many hours on the road until a car passed to take them to a health center.

Safia, a twenty-year-old Fulani, labored at home for two days before her family decided to send her to a health center. However, because there was no regular transport available, her family had to get together over 100,000 fcfa (approximately \$200 USD) to rent an entire taxi for her (the cost of which is typically shared among many passengers), “My family had to sell a cow to get the money. It took some time for them to find a buyer. We waited a very long time for my father to get the money. By the time we reached Zinder [hospital] I was already unconscious.” Maou, a fifty-year-old Hausa woman spent her entire labor at home. She explained, “In my village, there were no cars, no motorcycles, no mule carts. Nothing! If someone was sick, a group would carry her above their heads on a stretcher. Like that it would have taken days to get to the health center.”



Figure 9.4: Educational materials painted on cloth in French and Hausa used to educate rural villagers in Niger about obstetric fistula prevention, aimed at addressing second phase delays. “How to obtain help? If there is no telephone reception, go to the closest CSI (health center) in a mule cart”

Intervening to Reduce First Phase Delays

Since the early 2000s, the Nigerien state has made laudable efforts to increase access to maternal and child health care. In 2006 the government increased financial access by eliminating user fees for pre-natal care, caesarean sections, gynecological cancers, contraception, and health care for children under five years of age (which also increases mothers' familiarity and comfort with health centers themselves) (Ousseni 2011). As a result, the utilization of services has markedly increased. Between 1992 and 2006 the percentage of rural women in Niger who delivered in a health center remained between 5-8%, but almost tripled in the six years between 2006-2012 (see Table 9.3). As a result, homebirths dropped from 91% in 2006 to 77% in 2012.

Place of Delivery of Rural Women in Niger Using All Available DHS Data		
	Health Center	House
2012	21.8%	77.6%
2006	7.9%	91.5%
1998	8.1%	91.1%
1992	5%	94.4%

Table 9.3: This Table highlights the percent distribution of live births in the five years preceding the surveys by place of delivery of rural women in Niger for all available Demographic and Health Survey Reports (1992—2012). Due to increased focus on interventions aimed to promote birthing in health clinics (such as the reduction or elimination of user fees for most maternal health services), there has been a dramatic increase in the utilization of health centers, evidenced by the jump from 8% of births in health centers to 20% in just six years.



Figure 9.5: A health worker trains a village volunteer on fistula prevention using educational materials painted on cloth in French and Hausa. “It is important to go to the health center [CSI] to give birth”

Many maternal health interventions generally and fistula prevention campaigns specifically position the reduction of first phase delays (or prolonged labor at home) as the cornerstone of strategies to reduce maternal mortalities and morbidities in Niger. Many of these interventions focus on changing cultural practices or addressing familial neglect that discourages women from seeking appropriate care in a timely fashion. The implicit message is that the fewer women who birth at home, and the less time they spend there, the fewer maternal casualties, thus, the fewer fistulas. Indeed, many fistula reduction and eradication campaigns have been based on this over-simplified assumption.

As a result, many interventions are focused on discouraging home-births. In a study conducted by a team of physicians on women with fistula in Niger, the authors conclude that, “Culture and religious practices in Niger limit women’s access and use of the existing medical care system” (Meyer et al. 2007:90e3). The article continues, blaming “cultural beliefs surrounding childbirth” whereby women “believe that it is unlucky to deliver outside of the family home” (ibid.). They also place blame on Islam, “The population of Niger is 95% Muslim... These women appear to have a strong sense of fate within their faith... the women believed that they were in the hands of Allah and that it was not their place to question the reason that things occurred the way they did. Believing that divine intervention would protect them certainly inhibits their ability to be proactive about their healthcare” (ibid.). Thus, the authors advocate for “culturally sensitive advocacy campaigns on maternal health and fistula formation [that] may help communities to recognize troubled labors earlier in the process” (Meyer 2007:90e4). Fistula prevention campaigns modeled like this promote “community education” and the “empowerment of women” while discounting the importance of systemic reform of

health care systems. However, as discussed below, these initiatives may not be effective in accurately targeting the principal factors that contribute to the development of fistula.

Third Phase Delays: Prolonged Laboring at the Health Center

Of the 97 women in my sample who developed fistula due to childbirth, only 12 did not at any point during their labors seek biomedical attention. The remaining 85 women sought medical care (29 of whom did so within hours of the start of their labors) but experienced referral delay, horizontal rather than vertical referral, and clinician negligence (including clinical malpractice and abuse).⁸⁴ While the dominant narrative in prevention campaigns situates fistula as the result of first phase delays (prolonged labor at home), women's reproductive histories underscored the harmful effects of third phase delays (or delays in receiving appropriate care once at a health care facility), suggesting that the quality and timeliness of biomedical care received by rural Nigerien women may be the most critical factor in mediating morbidity risk.

9.5 Qualified Care, Not Just Care

Broken Referral Chains

The narrative of twenty-five year-old Zali's protracted delivery of her twins captures the frustration, physical pain, neglect, and broken system of referrals experienced by many women I spoke with in health centers. Although she began her delivery at home, she spent over a week moving between four health centers and two hospitals in a largely futile attempt to access care:

I started my delivery at home, and I spent two days in labor before I went to [Health Center 1] to seek care. There, they told me to go home. I was in too much pain, so I spent two days at that health center, but they didn't even touch me. I finally went back home and spent another day in labor. The baby wouldn't come, so my parents put

⁸⁴ Similarly, Mamane (2014) found that of his sample of new cases of fistula across three regions of Niger, 56% had completed prenatal consultations during their pregnancy, and 59% labored in a medical center.

me in a mule cart and took me to [Health Center 2]. I had gone there for a prenatal consultation, and it was the day of consultations when I arrived. So, I had a consultation but did not tell them I was in labor. The midwife saw that I was in labor, but she sent me home anyway. I spent another day at home before returning to [Health Center 2], but the doctor wasn't [at the center] and he refused to come. After a day, he came and gave me a shot—my pain was very strong then. The doctor went back home, and I spent the night alone there. The pain was too strong, so [my husband and parents] decided we would leave to go to [Health Center 3]. But, at [Health Center 3], they said they could not do anything for me and sent me to [Health Center 4]. There, I finally gave birth. I spent one week there before I lost consciousness.

Finally, the nurse called an ambulance to send me to [Regional Hospital 1] because there was still another baby inside me. I wasn't awake [conscious] and don't know what happened there, but I was told that the nurses used their hands to get the rest out. When I woke up, they didn't tell me anything, but saw there was a leak and they sent me to [Regional Hospital 2] because they didn't have medicine for my sickness. I went to [Regional Hospital 2] and waited for seven months there before receiving surgery [for fistula]. I was still very sick and couldn't even stand up.

Zali spent over seven days in labor with her first child (and seven more laboring with her second), only two of which were at home. Zali was refused care while in active labor by three practitioners, and referred horizontally (to health centers with similar capacities) rather than vertically (to higher level of care centers) once. Ultimately Zali visited four health centers and one hospital before being referred to a sixth health center where she was treated (unsuccessfully) for the devastating traumas incurred by her poorly managed obstetric catastrophe.

Nigerien fistula surgeon Dr. Lucien Djanikbo explained to me that referral delays might not be caused by malice of practitioners, but rather the lack of competence to recognize when a delivery has stopped progressing:

It isn't that the person [nurse or midwife] refuses because they want to refuse. Maybe it is because the person isn't competent enough to see that there is danger... The question is does the midwife have the competence to know when the situation surpasses her skills? Once I received a case a uterine rupture. When the woman couldn't walk anymore, she went to a CSI [mid-level health center]. The nurse there didn't understand what was happening, he didn't see how serious her symptoms were, and he didn't do anything. The family saw she wasn't getting care—and asked to be referred. I assume they asked many times, because he eventually wrote that he was referring her against his own wishes. He wrote: “referred by repeated demands of parents” to excuse himself for what he thought was an unnecessary referral. But [the referral] saved her life.

As demonstrated by Dr. Lucien's reflections, the system of referrals in health centers is political, representing a delicate balance between professionalism and reputation (as practitioners feel shame in unnecessarily referring) and respect of the safety of women and the acknowledgement of the limitations of one's capacities. The majority of women with whom I spoke were referred to two or more health centers (and as many as six) before finally delivering. However, women experienced referral delays and horizontal referrals to health centers of similar levels of care rather than vertical referrals to health care centers with better-trained clinicians and better-equipped centers. Additionally, as noted in Dr. Lucien's quote, referral letters are often used to exculpate oneself from blame and refocus blame elsewhere.

This was the case with Amina, a thirty-year-old Hausa woman, who was blamed in the death of her own child. Amina knew that her fifth labor was not normal. She felt a pain that was unlike what she experienced in her previous deliveries. She went quickly to the health center, but spent three days horizontally referred through three health centers. When she arrived at the final center, the nurses blamed her for the death of her baby:

On my referral paper it was written that I didn't come on time to the center, that it was my fault. But I had spent the previous three days in the health center! The nurses scolded my mother and asked her why she left her daughter to suffer until the baby's head had already come out. The nurses were very angry at us. They blamed the death of the baby of my family's neglect!

The Refusal of Care and Clinical Negligence

Twenty-six year old Lahiya was refused care due to a confusion surrounding a large fibroid that obstructed her labor for three days. The government-trained midwife in her local health center mistook the visible fibroid for the head of the child and assumed that Lahiya's inability to deliver was due to a "lack of courage." Lahiya's referral to a higher level of care was delayed for two days, and necessitated a large bribe from her family before the midwife

acquiesced. Even after Lahiya was referred to a higher level of care, the midwife called the reference center to state her opposition to the referral, suggesting that Lahiya should not receive a C-Section, but be forced to “show courage” and deliver vaginally. Lahiya’s story demonstrates the politics of referrals, the inadequacy of practitioner training at lower levels of care, and the ways in which “idealized birthing” that prioritizes stoicism and the mastery of pain articulates with the provision of emergency obstetric interventions in rural Niger.

Twenty-five-year-old Rabi’s labor story was also rife with clinical negligence. She explained that when her labor began, the nurse in her village consulted her right away, “The nurse said that there wouldn’t be a problem and that I would deliver by nightfall. I stayed the night at the center, but nothing happened. The head of the child was visible, but it wouldn’t come out.” After a day and a half, Rabi was referred horizontally to another health center in a neighboring village. She stayed in that center for two days. “Every hour the nurse would push on my stomach. I couldn’t urinate for three days. The nurse took a needle to take out the urine, but when he put the needle in, urine didn’t come out, only blood. He put the needle into the baby. When the baby was taken out days later, I could see where he was stabbed.” Eventually, an ambulance was called and Rabi was referred to a higher level of care. She recalled, “When the ambulance came and got me I was dizzy and I couldn’t see well. They cut out the child and the placenta was completely destroyed. It was in pieces. The child was swollen. When he came out, the whole room filled with the nauseating smell of his dead, rotting flesh.” Rabi birthed for a total of four days, all of which were in State-run health centers:

Everywhere I go they ask me if I had a long birth. They ask if I stayed a long time at home before going to a health center. But, I went quickly to a health center when my labor began, so I don’t understand why this sickness caught me.

Nafisa, a thirty-year-old Zarma woman, also believed that her fistula was caused by poor-quality nursing. She explained:

My fistula, it was the fault of the nurse in my town. I went to the health center as soon as my labor began. When the complications began, I asked that he send me to another center, but he looked at me and refused. He said that he didn't see any complications. He pushed on my stomach with too much force. Some people have hard hearts... A day passed until he sent me to another center. At that center, the nurses refused to touch me when they noticed the problem. They told me to continue on to another center. So, we went to the third center, but they said they couldn't do anything for me there either. Finally, two days later, I arrived at the hospital in Dosso. But, by then the child was already dead.

For an entire day Nafisa requested that the first nurse write a referral letter, but he refused.

Nafisa's experience at the health center caused anger within her community:

Many say it is because the nurse didn't refer me early enough that I got this sickness. They think it is his fault. Other women have had bad experiences there too. A neighbor lost her two children because of what the nurse did, because he pushed on her stomach. Now, women will not wait there anymore. Even if he refuses to refer them, they will leave.

While women in Nafisa's village preferred home birthing, fearing the center and its perceived outcomes, women no longer had the right to stay home:

In my village, now if a woman stays at home, she is fined 5,000 fcfa (approximately \$10 USD), but at the center she only pays 1,000 fcfa plus soap... Women who have money don't go to the center. They would rather pay 5,000 fcfa than go there and be mistreated. Or, if a woman's family is from another village, she can go there and not have to go to the center. But for the rest of the women... well, the rule isn't just, but I can't do anything about it.

Criminalizing Homebirths and Clinical Abuse

In an effort to decrease maternal mortality and morbidity rates (and potentially to increase profitability of local health centers) thought to be caused by prolonged first phase delays, many women reported that their village chiefs (working with local health agents) banned home births, as was the case in Nafisa's village. Women who refused to birth in the local health center were subject to a fine, the amount of which varied from village to village. Women are

thus expected to birth in their local *case de santé*, or health center, which is often little more than an empty concrete building with few, in any, supplies and staffed by a nurse with very little training.

Hagera, an eighteen-year-old Zarma woman who developed fistula following her first delivery, was in labor for seven days, all of which were at health centers. In Hagera's village, there was a steep fine—20,000 fcfa (approximately \$40 USD)—for home birthing. So, as soon as Hagera's labor began, she went to her local health center. However, these 'safe motherhood' initiatives only work when the care women receive in clinics is better than no care at all. For Hagera, this was not the case. "The nurses there do not care for women well. If women go to consultations, the nurses and midwives insult them for no reason. Sometimes they call the women 'bastards', other times they won't even consult them and send them away," Hagera averred.

Hagera paid the health center 10,000 fcfa (approximately \$20 USD) plus the cost of all medicines and supplies, quite expensive compared to other health centers that typically charge between 1,000 and 5,000 fcfa for an uncomplicated vaginal birth.⁸⁵

In the health center, the nurse pushed on my stomach and a fat midwife sat on my stomach. They didn't give me any medicine, and they wouldn't let anyone enter the room. Not even my mom to give me food... They hit my mom when she tried to come in to see me and give me something to eat. I spent three days without eating in the center.

Hagera recalled the kind of interventions that the nurses and midwives provided, "There were three women working at the center. Two women would hold down a woman and the other

⁸⁵ The main maternity hospital in Niamey (which receives referrals from across the country for obstetric complications) charged women 13,500 fcfa (in 2013) for vaginal deliveries (although Cesarean sections are free throughout the country, paid for by the state and international safe motherhood initiatives).

would push on her belly or sit on her.”⁸⁶ When Hagera was in the delivery room, there were four other women also in labor. None was allowed visitors. Hagera remembered that one woman died “because they used so much force trying to get out the baby.” “After they finished with that woman, they came to me. I was scared. When the nurses left the room, I snuck out and ran away. I found my mom and explained what happened.” Along with the other women who also ran from the center, Hagera and her mother rented a taxi to go to another health center in the nearest large town.

In the next health center, Hagera waited three days before anyone would consult her. Finally, the workers also tried to push on her stomach. She explained that they even used a piece of wood to hit her stomach. “They didn’t do a cut [C-Section] because there was a power outage. One woman was being operated on when the power went out, and she died. So my parents refused to allow them to do this procedure on me.” Knowing the dynamics between clinicians and patients in rural centers (and the disdain many practitioners have for noncompliant patients), I asked Hagera if the staff punished her for refusing the C-Section. She responded that yes, they did, “They ignored me for another three days before even looking at me again.”

On the seventh day of her labor, Hagera had lost consciousness and was sent to Niamey. Within an hour of her arrival, Hagera was operated on. She did not regain consciousness until a week following her surgery, finally waking up to the news of a stillborn child, a fistula, and the blood stained bandage from an emergency hysterectomy.

Whether of their own initiative or incentivized by steep fines, women reported heading to health centers as soon their labors began only to birth alone at unmanned health centers; to be referred horizontally; to be monitored by untrained health assistants; to be left unassisted when

⁸⁶ “Abdominal expression,” as it is known locally, where excessive force is placed on a woman’s abdomen to encourage the birthing of the baby, is a common practice in low-level health centers in Niger.

nurses' or midwives' working hours ended; to be forced to bribe nurses, midwives, or health assistants for referrals; to be punished for non-compliance or failure to consent to procedures; or to be subject to ineffective and dangerous interventions such as “abdominal expression.”

Nigerien fistula surgeon Dr. Lucien Djanikbo explained how many obstetric morbidities in Niger are due to a lack of competence of practitioners in health centers:

What could save mothers and children, what could avoid fistula, is to give birth with a *qualified* attendant—to give birth in front of a *qualified* person. This is different than giving birth in a center. If the person [nurse or midwife] at the center isn't competent, if he can't follow a partogram,⁸⁷ he will not have a good attitude towards women. He may mistreat them. One can't just build a center and assume that maternal health will improve. Who will work there? What is the competence of the attendants? ... The quality of the training of midwives and nurses isn't good here. There is a recruitment problem. Anyone can get in [to nursing programs]. There is also a lot of corruption—you pay tuition and you are in. Many people who get a diploma don't have competence... There are midwives who go through three years of training, three years of school, and still don't know how to follow a delivery! How can she get a diploma? She pays for it! A midwife or a nurse who works with delivering women—if that person can't say if the birth is going well, there is no reason to let a woman go there. In the bush, if these people see the head of the child, they think that if they use force and push [on the woman's stomach] it will come out. And sometimes it does. But other times, it doesn't. And when a woman is tired, they will try everything.

Similarly, in a study conducted with women with obstetric fistula in Tanzania, Mselle et al. (2013) estimated that while 50% of births in Tanzania occur in health facilities, only about half of those are attended by skilled personnel. Their findings indict the health structures of Tanzania, whereby laboring women frequently complained about practitioner malpractice, neglect, and abuse, nurses and midwives blamed the poor quality of care on the lack of materials and shortage of clinicians, which impeded them from effectively providing care:

While focusing on increasing the number of health care workers, there is also a need to ensure that nurse-midwives have the necessary competence to work in the labour ward... some of the women in this study received an unwelcome reception during admission onto

⁸⁷ A partogram is a graphical record of key maternal and fetal data during labor (with indications for normal birth progression measured through markers such as cervical dilation, fetal heart rate, duration of labor, and vital signs of the mother). The partogram is intended as a low-cost, low-technology rubric for detecting delays or deviations from normal labor progression (facilitating the rapid detection and treatment of obstetric complications).

the labor ward. Some of them were left to give birth alone without assistance. Some revealed that when they shouted for help, the nurse-midwives did nothing. In the few cases, when nurse-midwives came at all, some of the women experienced verbal and physical abuse. (Mselle et al. 2013)

In a study conducted on obstetric fistula in Nigeria, Murphy and Baba (1981) similarly found a lack of basic and necessary equipment in health centers and “an acute shortage of qualified nursing staff” (267). Locals regarded health centers and hospitals as “a place to die” and, noting the relationship between first and third phase delays, “this became a self-fulfilling prophecy as patients delayed coming to hospital until it was too late to help them” (ibid.).

9.6 Length of Delays: Interrogating the Data

Thirty-percent of women in my sample sought care within hours of their labor beginning for the birth that caused their fistulas, while 88% eventually sought biomedical intervention. The 97 women in the sample who developed fistula due to childbirth labored for an average of 3.0 days (± 1.8) (see Figure 9.6).

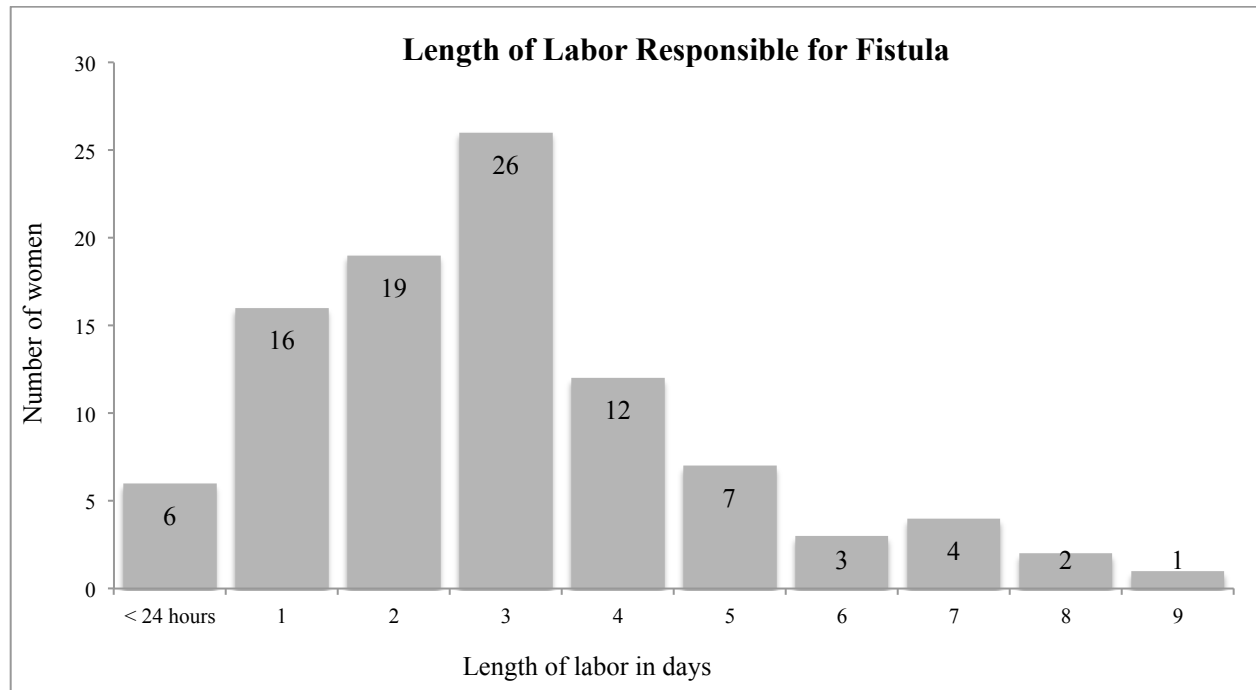


Figure 9.6: The length of labor responsible for fistula of the full sample (N=97). The average labor was 3.0 days (± 1.8).

The average length of laboring for women who birthed almost exclusively at health centers (defined as women who either went to clinics immediately after their labors began or stayed at home only “hours” before seeking care) was 2.1 days (± 1.7) (see Figure 9.7), while the length of laboring for women who birthed exclusively at home (never seeking care at health centers during the labor) was 2.6 days (± 1.9) (see Figure 9.8). Meaning that the length of laboring for women who birthed almost exclusively in biomedical centers is not significantly different from the length of labors of women who birthed entirely at home ($p=0.45$).⁸⁸ Although there may be several confounding variables, this suggests that the quality of care women received at health centers was poor, demonstrated not only by poor outcomes but by prolonged delays to access care.

Interestingly, both of these groups of women had significantly shorter labors when compared to the remaining women in the sample (women who neither birthed entirely at home nor entirely at clinics) who labored for an average of 3.4 days (± 1.8) ($p=0.008$).⁸⁹ This suggests that the women who labored entirely at home had slightly shorter labors than the average woman (2.6 days compared to 3.0 days for the full sample or 3.4 days for the women who birthed neither entirely at home nor entirely at health centers) and may have eventually sought care had their labors continued to be obstructed.

⁸⁸ Calculated by comparing the length of deliveries of women in the two groups, $p=0.45$.

⁸⁹ This was calculated by comparing the length of time of deliveries of women who birthed either entirely at home or at a clinic against the remaining women in the sample using a 2-Tailed T-test, $p=0.008$.

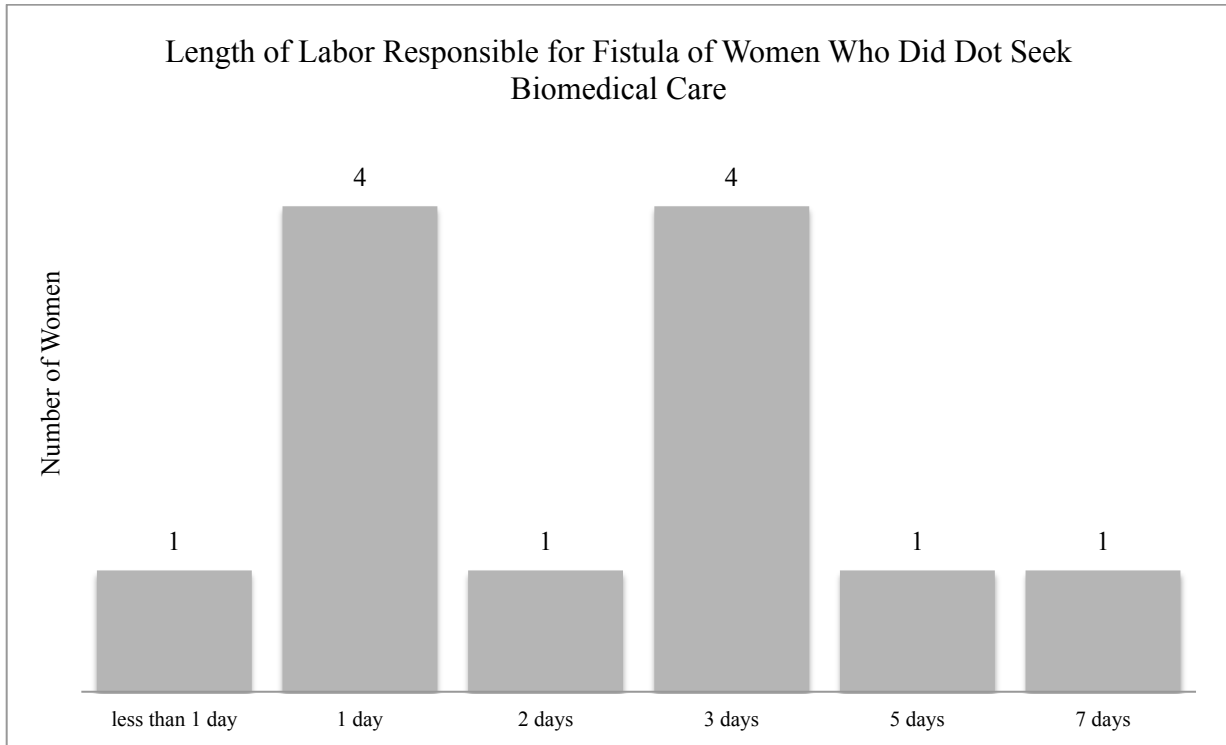


Figure 9.7: The length of Labor Responsible for Fistula for the 12 women who did not seek biomedical care. The average labor of 2.6 days (± 1.9)

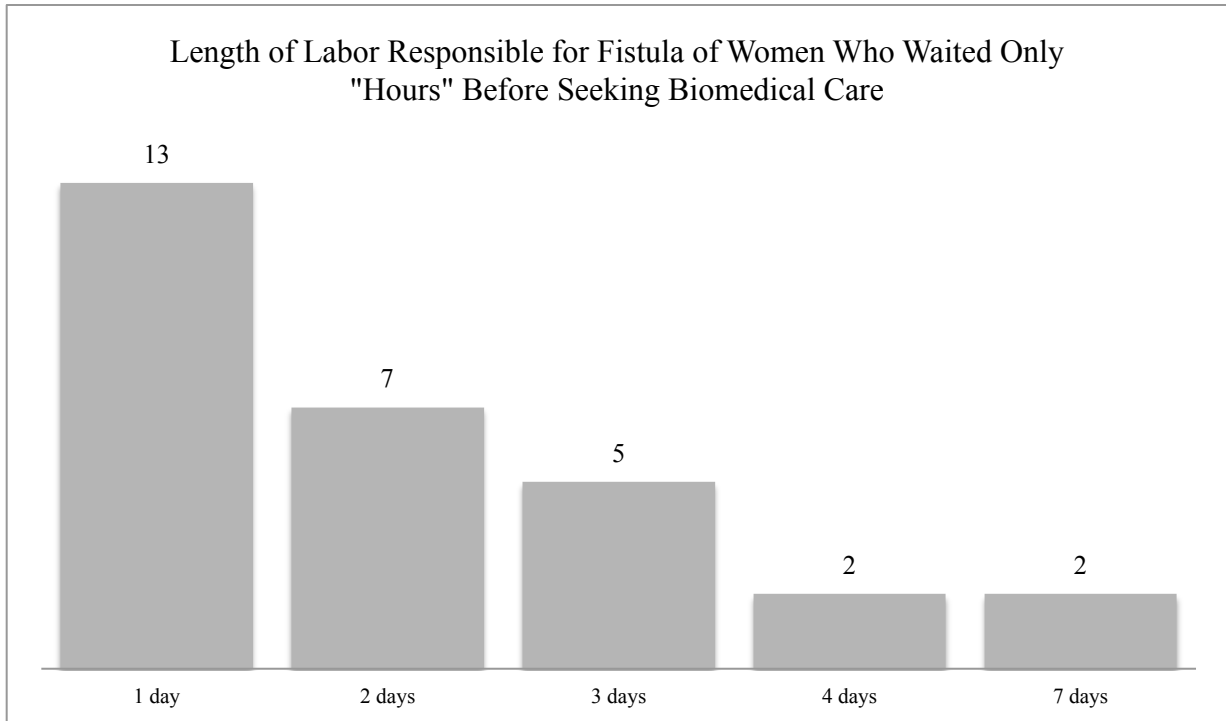


Table 9.8: The length of Labor Responsible for Fistula for the 29 women who immediately sought biomedical care. The average labor lasted 2.1 days (± 1.7).

My data are similar to those found in a study conducted by UNFPA and Niger’s Ministry of Health that included a universal sample of all women entering any of the six fistula repair centers in Niger in April 2013—a total of 178 women. In total, only 16% gave birth at home, while 84% birthed in State-run health centers (3% birthed at a case de santé—local health center, 15% birthed at a CSI —regional health center, 35% birthed at a district hospital, and 30% at a regional maternity referral center). Dr. Hassane Boukary Doudou, the head of UNFPA in Niger explained at an international conference in Niamey in October 2013, “A huge majority of women with fistula give birth in a hospital” (Doudou 2013).⁹⁰

Patently, access to care is not the same as access to quality care. Fistula can be caused by a poorly trained clinician keeping a woman at a center for far too long, refusing to refer her to a higher level of care, referring her horizontally rather than vertically, or performing forceful and inappropriate interventions in the face of an obstetric complication. This decenters the popular public health prevention approach whereby ‘changing the culture of birthing’ and ‘raising awareness’ about the importance of birthing at a health center is sufficient towards lowering incidence of fistula.

9.7 Women’s Perceptions of Iatrogenic Fistula

It is unsurprising that many women in Niger have a deeply engrained mistrust of biomedical care. As twenty-seven year-old Hasana explained, “Women are afraid to give birth in centers—it is the fear of dying. If women go to centers, they will suffer much more than at home... Most women who die, they die at the health center. Most babies too.” Women consider their bodies as completely capable of unassisted and non-medicalized birth, and often, even in

⁹⁰ Similarly, a controversial study conducted by an epidemiologist working for Niger’s Network for the Eradication of Fistula under the ministry of health showed that contrary to popular belief, most women with fistula were not birthing at home, but at state-run health centers (Mamane 2014).

the face of an obstetric complication, blame fistula not on birth gone awry, or on their own bodies, but rather on a medical intervention itself.

Iatrogenic fistula, or fistula induced inadvertently by a practitioner during medical treatment—often caesarean section, forceps delivery, or manual extraction, is thought to account for approximately 10-15% of fistulas worldwide. While C-Sections are widely understood to be an important key in the prevention of fistula, they are also a risk factor. In a study about fistula in Uganda, a fifth of the country's fistula were found to be the result of poor quality health interventions, specifically, "21% of the country's cases are the result of human error, often occurring during C-Sections (a dark irony, given that C-Sections are also needed to help prevent fistulas)" (Kardas-Nelson 2013).

A visiting Sudanese fistula surgeon who came to Niamey as the head of a surgical mission team explained to me in June 2013:

The problem here is that they don't talk to the patients. Sometimes if I take out a uterus, I explain that it was to save your life. Here I think that they don't have respect for the patients. It is just a personal feeling... It is totally different in Sudan- we have a medical council there that will follow you if you make mistakes. A doctor has rights, but so do patients. There are consent forms and women must sign them before surgeries. The situation is totally different here... There is no accountability for practitioners if they make mistakes. Here they have a policy of training doctors to do a lot of C-sections to reduce fistulas, but they are actually causing them. I am trying to find an excuse for these doctors, like the working situation. ... The lights flicker—sometimes they don't stay on for a minute. And in a bad situation, saving a woman's life might be more important. But, this can also be an excuse for bad work.

Still, given a context of medical mistrust, even more women may *perceive* that their fistulas were caused by medical intervention than actually were. While approximately 20% of fistulas in sub-Saharan African countries are suspected to be iatrogenic, a much larger proportion of women with fistula may blame biomedical practitioners for their fistulas. In my sample of 100 women, 29 women (29%) expressed a belief that their fistulas were caused by a biomedical

healthcare provider. For example, Habsu, a forty-five-year-old Zarma woman with fistula I spoke with, said: “It comes from God—still, all of the women here have it because of hospitals, because of midwives.” In a retrospective analysis of hospital records of women with urogenital fistula in the Democratic Republic of Congo, Onsrud, Sjoveian, and Mukwege (2011) have even more dramatic findings. They find that that 24% (55/229) of women who delivered via cesarean had a presumed iatrogenic fistula, yet *all* women believed that their fistulas following vacuum extraction, cesarean hysterectomy, or other obstetric interventions were caused by those procedures (Onsrud, Sjoveian, and Mukwege 2011). According to Bangser et al. (2011), 84% of women in Uganda believed that their fistulas were iatrogenic, caused by practitioners accidentally puncturing their bladders or using force or dangerous instruments (such as forceps) during delivery.

A fistula may be wrongly attributed to a caesarean section by a woman who underwent the medical intervention after a prolonged obstructed labor (at which point the damage to her pelvic tissue may have already occurred) due to Nigerien women’s relative unfamiliarity with and fear of the procedure. Since the government of Niger made caesarean sections free for all women, the C-Section rate has steadily increased to 1.4% nationwide (and 0.8% among rural women) from 1.0/0.3% in 2006 and 0.6/0.3% in 1998, but it remains very low (DHS 2012; DHS 2006; DHS 1998). Mariama, a thirty-five-year-old Hausa woman with fistula, explained: “For me, I think that it is the operation. I had never had a caesarean section before. All I know is that when they operated they cut something. I gave birth so many times and didn’t have fistula, but I never had a caesarean.” Mariama’s thinking demonstrates the type of probabilistic thinking, whereby for many women, the delivery which caused fistula was their first encounter with biomedicalized birth.

Hasana, a twenty-seven-year-old Zarma woman, explained that although she did not believe that her fistula was iatrogenic, everyone in her community did:

People in my village said that it was the nurses that hurt me during the labor—that caused my sickness. But, I don't agree. It was the birth. I already had a problem when coming to the center. So it wasn't their fault... People in my village, they say, "Hasana went to the center to give birth, but came home with fistula!" So, they won't give birth at the center. They will only birth at home.

Abou, a fifty-year-old Hausa woman who developed fistula during her eighth delivery (following seven uncomplicated home births), suggested that long labor causes fistula, but added, "Also the midwife. When she puts her hand inside a woman, it can bring sickness. Some women have long labors and they are not taken to the health center. After, they are fine. But when the midwife puts her hand inside of you, she touches something, and it is at this time that the sickness starts."

Many women expressed suspicion of bio-medical intervention's efficacy and safety. This type of probabilistic thinking is understandable considering women's sample size—most women in rural Nigerien villages can attest to the relative safety of home births (based on a large sample size, often intensified by their own personal experiences with uncomplicated and safe prior home births of their own). While maternal and mortality rates are high in relation to more developed nations, they are still low enough so that a woman in a small village may know few women who had negative outcomes birthing at home. However, the bias inherent in their samples of biomedical births may result in their perception of its exaggerated risk. Indeed, the prevalence of poor health care (particularly poorly trained practitioners) propagates the underutilization of health care systems and the lack of confidence in these systems as health centers are only used in emergencies, when outcomes are likely to be poor.

* * *

With the highest total fertility rate in the world (at 7.6 births per woman, DHS 2012), Nigerian women place tremendous importance on the ability to conceive, birth, and mother children. Through the idealized silent, solitary, and stoic homebirth, women gain social value and internal pride. However, for most women with fistula, an idealized birth was not possible. Many women with fistula were expected to brave the extreme physical pain of obstetric catastrophe, only to endure the ensuing social and emotional pain of childlessness and social invisibility and devaluation.

When an idealized homebirth fails to progress normally, women and their families are often left with few options. Due to the valorization of birthing alone, local midwives, or *ungozoma*, have little experience in detecting or treating obstetric complications with physical maneuvers and instead rely on prayer and ceremony to address medical emergencies. The three-phase delay model is used to help disentangle where, when, and why women do not receive rapid medical intervention during obstetric emergencies (Thaddeus and Maine 1994).

Although the assumption is that women with fistula have waited a dangerously long time at home, this is frequently not the case. While some women I interviewed did spend days in labor at home without reaching out for biomedical care, 33% of women reported heading to their local health clinic as soon as their labor began. They tried to deliver at health centers, but experienced poor medical treatment, including referral delays, refusal of services, physical and verbal abuse, inappropriate interventions, and botched Caesarean sections and episiotomies.

Typically women do not suffer just one phase of delay, but often all three. Women wait too long at home, it then takes women too long to get to a clinic, and when they do arrive, it takes too long to receive quality care, which sometimes never comes. Additionally, second and third phase delays can exacerbate first phase delays in future decision-making. Just as previous

positive experiences seeking care may reduce future first phase delays, negative experiences with the health care system may decrease perceived benefits of seeking care while increasing perceived costs, resulting in more time spent at home and longer first phase delays.

The current portrayal of fistula displaces a focus on structural inequalities of multiple scales in favor of condemning local cultural inadequacies, including practices and beliefs that discourage women from rapidly seeking biomedical care in the face of an obstetric complication. In an article entitled “Niger: Why Are So Many Mothers Dying?” IRIN suggests that high rates of maternal mortality and morbidity in Niger are due to individual poverty (excluding women from paying for adequate care), poor transportation infrastructure, low levels of education, reliance on “religious officials and traditional healers,” and “a lack of awareness of women’s rights” (IRIN 2007c). The article concludes by quoting a UNFPA officer: “We could have the best healthcare facilities in the world here, but if people don’t understand why it matters, they won’t go” (IRIN 2007c).

Based on the assumption that the fewer women who birth at home, and the less time they spend there, the fewer fistulas, fistula eradication campaigns are focused on discouraging home-births rather than investigating why women opt out of clinical deliveries in the first place. Birthing at clinics (many of which are burdened by chronic shortages of trained personnel, drugs, equipment, ambulances, electricity, and water) is uncritically framed as the key component to fistula prevention. Even if health clinics proved effective for managing low-level birth complications (which this research suggests that they may not), the vast majority of health facilities are unable to perform C-sections in the event of obstructed labor. Niger has over 17 million people and more than 700,000 births a year, yet only 17 obstetricians are trained to perform C-sections in the entire country, 7 of whom are based in the capital city (IRIN 2007c).

PART III:

RE-THINKING STIGMA AND FISTULA

Aissa's Story: Fistula-Stigma and Expert Testimony

Aissa, a twenty-seven-year-old Kanuri woman who had lived with fistula for over ten years, was full of vigor. Some might even have called her abrasive. She was always the loudest and most outspoken woman at the fistula center. She spent her days carefully tending to her make-up, drawing 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 of many Kanuri women from southeastern Niger. From a very religious home, where both her father and husband were *marabouts*, local religious leaders teaching Quranic school, Aissa could read some Arabic—a marker of status among the pious but largely unschooled women at the center. She often taught the other women how to read Suras from the Quran and pray correctly, frequently blurring the lines between instruction, preaching, and scolding. Often when I would see her at the center, she would carefully apply extra make-up and pose with her prayer beads and cell phone on her woven mat, grabbing my camera from my sac and demanding yet another photograph to capture her modernity.

When I first met Aissa, she was harsh, lanced insults easily, and refused to be interviewed. But, I grew on Aissa, and after several months, she pulled me aside and questioned why I had not asked to interview her again, “We are friends aren’t we?” She was reclining on her bed, attached through a catheter to a bag that collected her urine. A week before, she had received her eighth surgery. On this day she was full of hope and wanted to tell me about her life. So, ten months after she had arrived at the fistula center, I sat with Aissa and listened to her story.

At the age of fourteen, Aissa was married to an older man—the first cousin of her father. She did not know the man; she had never even seen him until she was 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’s moved to her husband’s house,” she told me. But Aissa did not want to be married, and refused to accept her fate. For one year after her marriage she refused to pass the night at her husband’s house. As soon as she was deposited at his house, she would sprint right back home. Every day her father would beat her, furious at her disobedience and humiliated by her impertinence. “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 (indeed, she had not wanted Aissa to marry the man in the first place). But, as Aissa said, “wives have no power compared to their husbands.” Her mother eventually left her father over the disagreement, and then she was left without an advocate at all.

Still, what made Aissa finally accept her marriage was neither physical violence nor its threat, but (according to her), the nefarious forces of the occult. Aissa explained that her father and her husband commissioned a potion from a local sorcerer. The concoction was mixed into a bottle of perfume that was poured over her head while she slept. When she awoke, she had a terrible headache that only worsened over the following week. Eventually, she had no choice but to accept her husband. Once she submitted, the pain stopped as abruptly as it had begun.

Although her husband was not unkind, life with him was difficult. She 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.

She miscarried both her first and second pregnancies, which only worsened tensions at home. As soon as she knew that she was pregnant with her third, she was resolute that she

would not spend her pregnancy in her husband's home. But, when she went to her father's home, he exploded in anger, furious that she continued to disobey his wishes. He refused to let her stay in his home. So, Aissa sold what she owned in order to cobble together the necessary funds to cross the Niger-Nigeria border. She made her way to the surrounding villages of the Nigerian city of Maiduguri in hopes of finding her mother. By the time she arrived at her mother's natal village, following a long and arduous journey, she learned that her mother had already returned to her father. But, because her maternal extended family had opposed Aissa's marriage (as they had had their eyes on another young man for Aissa to marry), her aunt took her in when she fled.

Aissa was in labor for two days at home before being taken to a clinic. When her aunt noticed that the fetus had changed positions, the decision was made to take Aissa to a health clinic. After two horizontal referrals and on the fifth day, Aissa was no longer conscious. When she woke up, she was in a different hospital, lying in a different bed, soaked in urine. She learned that the body of her dead baby had been cut out of her, and what remained was a fistula.

She returned to her parent's home, but found life unlivable. She leaked. Neither of her feet worked. And she was mistreated. Her father interpreted her fistula as Aissa's comeuppance for her obstinacy and repeated defiance. For Aissa, 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.

Aissa's aunt took her to a hospital in Niger's eastern city of Diffa. Finally, after nine months of sleeping on a plastic mat in the hospital courtyard, she was told that they would not be able to operate on her there. She was referred to Zinder, a city 400 miles away. But in Zinder's

maternity hospital she was told that the doctors would not operate on her until her legs had healed. Remembering how difficult life was at home, Aissa decided to wait at the hospital in Zinder rather than returning to her parents' home. It took four full years for her legs to regain their function and strength. No one came to visit her during her four years in the hospital. In her fifth and sixth year at the center, she underwent five operations in Zinder. None were successful. "I leaked every day. I leaked all of the time. The operations did nothing."

Her father refused to come to see her because he was still angry with her. He never sent money. Her husband visited her twice when she was at the center in Diffa, but never again. He never sent money. He remarried three other women, and one year before I met Aissa, after courting another woman, he officially divorced Aissa so that he could marry his new girlfriend.

When I asked why she stayed at the hospital for so long, she became angry. "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?" she inquired forcefully. "If it wasn't paid for to come here to Niamey, I would never have come." A year after losing their only fistula surgeon (who as a government employee had been given orders to move to Niamey), the center in Zinder eventually filled a bus of leaking women to be shuttled the 550 mile distance to Niamey.

Some women are lucky to have someone that will take care of them, but others don't have that—that's what makes the difference between experience. Others have sicknesses that are much worse, some are better after the first or second surgery, but others are not. Some can even go to the toilet, or some it is only when they sleep, but me, it is all of the time. That's the difference.

Aissa became upset and mindlessly played with the ringtones on her cellphone. When she looked up, she told me, "This is why I don't like these questions. In Zinder, sometimes people would come to ask me questions; I would say that I didn't speak Hausa so I didn't have to

answer. It is too hard to say what kind of things your family has done to you. But because you've become my friend, I can't hide these things from you.”

A week later, Aissa's catheter was removed. I found her one afternoon curled up on her bed. Through her tears she told me that the operation did not work. She was still leaking.

Aissa went to stay with a family member in a neighboring town, and the next time I saw her was three months later, at an international fistula conference being held in Niamey. To open the conference, local representatives had brought two women to give their personal testimonies. Aissa stood in front of the large crowd, looking particularly cosmopolitan in her heavy makeup and shiny pink hijab that shimmered in the light. Through a translator, she told the crowd that because of fistula, her life was filled with sorrow and problems, but thanks to the doctors and donors, she was now dry, and would now have another chance at life.

A few days later, UNFPA published Aissa's testimony in an article titled “Taking Stock: Ten Years Fighting Fistula in Niger”:

“I wish to launch an appeal to our parents to stop marrying their girls so young. For me, under the age of 18, a girl should not be married,” said Aissa Boubakar, 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. Boubakar. (EndFistula.Org 2013)

At the break, I found Aissa in the bathrooms. “You're dry!” I exclaimed as I swung my arms around her, ecstatic about the news. With a downward gaze, she muttered, “No. I am still wet, but no one wants to hear that story...”

I never figured out why Aissa told the room full of fistula experts from across the globe that she was dry. Perhaps she crafted and deployed her own testimony to use for her own purposes. Perhaps she was asked to tell that room that she was dry by clinic staff. I often

stumble across Aissa's face on the websites of various NGOs, or in the adjoining photographs from international news articles on fistula. Aissa has become somewhat of a professional patient, having spent approximately nine out of the last ten years in fistula centers across Niger.

When I left Niger, Aissa was still waiting at the center for her ninth surgery. Aissa told me that her family had told her to stay at the center until she was healed.

Aissa's story reveals the complexities of the lived experience of fistula, particularly fistula-stigma, which will be examined in Part III of this dissertation. Aissa's narrative highlights how a woman's vulnerability to fistula-stigma is set long before her labor begins, determined by a complex set of social relationships and her position and power within them.

Chapter 10

Fistula-Stigma and Stigma Dynamism

In-line with classical formulations of social stigma, academic literature (as well as media and donor discourse) frequently regards fistula as a highly symbolic illness that alters social landscapes and reshapes personal identities. Indeed, most discussions of fistula (regardless of their genesis) at some point indicate that the condition is linked to extreme social stigma, which results in social marginalization and constrains women's abilities to seek treatment. Although the concept is frequently referenced, 'stigma' is rarely (if ever) explicitly defined or used with consistency and precision. Instead, a monolithic experience of social rupture and abandonment is evoked. See, for example, the following three quotations. The first is from the online encyclopedia Wikipedia, the second is from a peer-reviewed article in the International Journal of Gynecology and Obstetrics, and the third is from the women's health advocacy non-profit Women Deliver:

Physical consequences of obstetric fistula lead to severe sociocultural stigmatization for various reasons... Accounts of women who suffer obstetric fistula proclaim that their lives have been reduced to the leaking of urine, feces, and blood because they are no longer capable or allowed to participate in traditional activities, including the duties of wife and mother. Because such consequences highly stigmatize and marginalize the woman, the intense loneliness and shame can lead to clinical depression and suicidal thoughts. (Wikipedia 2014)

When the woman survives the ordeal and is left with an obstetric fistula, she experiences constant leakage of urine and/or feces. Once her fistula is established, her life is changed forever as she is no longer able to fulfill her societal roles of wife and mother, and is often deserted by her husband and stigmatized by society. Fistula is preventable and treatable, but still millions of women in developing countries suffer from this dreadful condition. (Ahmed et al. 2007:S1)

Obstetric fistula is preventable, treatable and far too common. Estimated to affect more than 2 million girls and women globally, up to 90% of fistulas are treatable with surgery. Yet somewhere between diagnosis and recovery, women experience staggering stigma, and many are even shunned by members of their community. (Menard-Freeman 2013)

In the rare cases when any depth regarding the meanings of stigma is offered, the discussion is typically restricted to a simplistic understanding of “spoiled identities” as defined by sociologist Erving Goffman.⁹¹ Alternately, stigma is indicated to be a consequence of mistaken etiologies of fistula (e.g., infidelity, witchcraft, and God’s punishment of sin, etc.). Very rarely are the meanings of fistula-stigma or its dynamism explored. Rather, ‘stigma’ is forwarded as a one-dimensional, fixed consequence of fistula, applied uniformly to all sufferers and resisting change over time.

In this chapter, I build on previous critiques of stigma to challenge this monolithic representation of fistula-stigma. By drawing from women’s experiences in Niger, I reconfigure fistula-stigma as a multi-dimensional concept. I do so with the aim of adding nuance to the experience of stigma in order to examine (1) what constitutes fistula-related stigma, (2) how, why, and when fistula-stigma is produced and reproduced, and (3) how local constructions of fistula-stigma serve the interests of various stakeholders and depend on structures of exclusion and inequality.

I situate fistula-related stigma within the extant corpus of stigma literature and focus specifically on the dynamism of fistula-stigma in Niger and its dependence on pre-existing power relations. I argue that it takes power to stigmatize and structural disempowerment to be stigmatized. Additionally, I situate fistula-stigma as a felt experience of women living with fistula. I found that the experience of fistula-stigma is highly variable, predominantly internal, and largely dependent on broader social and moral contexts that allow for (or prevent) the

⁹¹ For example, “The individual, family, and social-cultural experiences women living with obstetric fistula go through fundamentally destroy these women's identity” (Mselle et al. 2011).

production of fistula-stigma. Women's perceptions of their lived experiences with fistula minimize the prevalence of outward fistula-stigma, mistreatment, or avoidance behaviors while underscoring the personal, emotional, and psychological burden of the illness. However, I found that the minority of women who do experience high levels of external fistula-stigma are likely to be living without the protection of a mother and staying for significantly longer periods of time at fistula centers than their counterparts. Conversely, I found that the majority of women with fistula experience high levels of internal stigma—experienced as shame, feelings of ruined identity, and the loss of value and uselessness. This research counters prevalent assumptions about fistula-related stigma, reconsidering what kind of experiences constitute fistula-stigma and heightening our awareness to internal processes while relying less on primarily external processes and proxies.

10.1 Theorizing Stigma: Beyond Goffman

Over the years social scientists have employed the concept of stigma in order to explain the phenomenon whereby individuals are perceived as abnormal and thereby socially discredited. The concept of social stigma serves to elucidate why some individuals are valued while others are discounted, considered dangerous, or even grotesque. It has been investigated by psychologists, sociologists, political scientists, social geographers and anthropologists, all of whom aim to understand what stigma is, where it is located, and how it is assigned, reproduced, and resisted. Since the 1960s, concepts of stigma have been employed to investigate a variety of phenomena, including HIV and AIDS (Castro and Farmer 2005), mental retardation (Edgerton 1993), dwarfism (Ablon 1984), epilepsy (Ablon 2002), mental illness (Jenkins and Carpenter-Song 2008), leprosy (White 2005), infertility and pregnancy loss (Ellison 2003; Inhorn 2004), and childlessness (Riessman 2000), to name a few. However, because stigma has been applied

to such a vast array of circumstances (and by a vast array of researchers with differing theoretical orientations and objectives), definitions of stigma have been vague and constantly contested.

Much of the investigations of social stigma begin with the seminal work of sociologist Erving Goffman, who in *Stigma: Notes on the Management of Spoiled Identity* (1963) defines stigma as a socially undesirable difference, discrediting attribute, behavior, or reputation resulting from a process whereby one's identity is "spoiled" by the reactions of others.

According to Goffman, stigma acts as a mechanism whereby difference or deviance is regulated socially through rules and sanctions. Through the study of mental illness, physical deformity, and perceived social deviance (such as criminal behavior and homosexuality), Goffman argues that stigma is "a special kind of relationship between an attribute and a stereotype" (Goffman 1963:4). Stigma, then, is situated as a discrepancy between "virtual social identity" and "actual social identity," or how a person is socially perceived in relation to the attributes actually possessed by the person (Goffman 1963:2; Yang et al. 2007:1525).

Working within Goffman's framework, Jenkins and Carpenter-Song (2008) define stigma as a social phenomena constituting various forms of "othering" including rejection, discrediting, and distancing, which is thought to be attached to "conditions that are viewed as chronic and unremitting, and that are understood to be manifestations of social, spiritual, or moral transgression" (383). Using a similar theoretical scaffolding, health-related stigma is defined by Weiss and Ramakrishna (2006) as "a social process or related personal experiences characterized by exclusion, rejection, blame, or de-valuation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem."

While the social and psychological formulations of stigma that draw upon Goffman's work offer important insights into cognitive and behavioral processes resulting from social exclusion, many scholars are critical of these treatments of stigma. Critics contend that these approaches to stigma are constrained by simplistic understandings of social processes, an overly narrow focus on the individual (while ignoring the broader social context), a conceptual restraint of individuals to resist stigma, a neglect of dynamics of power and exclusion, and a positioning of stigma as a tangible *thing* rather than a process (see Parker and Aggleton 2003 and Yang et al. 2007 for examples). Out of these critiques grew novel approaches to stigma and theoretical frameworks for better understanding what stigma is and how it is created, reinforced, internalized, and resisted.

Link and Phelan (2001) argue that the standard model that asks what makes one person discriminate against another person is inadequate for explaining the "the full consequences of the stigma process" (372). Rather, they claim that critical to understanding stigma is to determine how culturally mediated categories arise and how they are sustained. Link and Phelan suggest that frameworks for understanding stigma would answer "Why is it that some human differences are singled out and deemed salient by human groups while others are ignored? What are the social, economic, and cultural forces that maintain the focus on a particular human difference?" (Link and Phelan 2001:372). These questions are particularly relevant when understanding fistula-stigma.

Parker and Aggleton (2003) also critique popular social-cognitive and behavioral models of framing stigma, arguing that when it is situated as a "discrediting attribute" or an "undesirable difference" which results in "spoiled identity" (as Goffman suggests), concepts of stigma then focus too heavily on the individual, leading to an understanding of stigma as a static attitude

rather than a dynamic, and frequently resisted, social process. Thus, in their analysis of stigma, Parker and Aggleton (2003) shift the focus from the stigmatized individual to the larger group, arguing that “stigma and discrimination, when and where they appear, are social and cultural phenomena linked to the actions of whole groups of people, and are not simply the consequences of individual behavior” (17).

Anthropological approaches to stigma tend to differ from those of psychology or public health because they emphasize the social dimensions of stigma, which are embedded in local moral contexts, and highlight lived experience, individual agency, and intersubjectivity. Yang and colleagues (2006) highlight that “across cultures, the meanings, practices and outcomes of stigma differ, even where we find stigmatization to be a powerful and often preferred response to illness, disability, and difference” (1528). Because stigma is so often disembedded from local social and moral contexts, many studies of stigma are criticized for misunderstanding and misinterpreting the experiences of both the stigmatized and the stigmatizers. In response, Jenkins and Carpenter-Song (2008) argue for a “meaning-centered approach,” or an intersubjective understanding of stigma where it is “produced and experienced in the interactive space between individuals in culturally defined social worlds” (382). In response to calls for such approaches to stigma, my research offers a “meaning-centered approach” to fistula-stigma.

Additionally, anthropological approaches to stigma are sensitive to cultural particularities of what is most “at stake” and thus threatened by social stigma, be it family ties, social circles, employment opportunities, or individual self-conceptions. Investigating stigma through the lens of dwarfism, Ablon (1984) looks at degrees of stigma, or the “status value gradient,” positing that the more value a society places on an attribute, the more stigmatized an illness will be which results in a lack or deficiency of that attribute. In contexts where a full transition into adulthood

is predicated on reproductive success, and a woman's worth is based on her purity, sexual submission, and role as wife and mother, fistula-related stigma can be productively understood within a "status value gradient," which challenges the conception of stigma as sited purely within the individual to one grounded in social space. Understanding fistula-stigma within a "status value gradient" helps to illuminate what characteristics of fistula might be positioned as specific conditions of exclusion—privileged beyond the ubiquitous corporeal symbols of ill health that mark the bodies of rural Nigeriens. Fistula-stigma can be interpreted as a way of reinforcing gender expectations and controlling women's sexuality in highly patriarchal sub-Saharan Africa. In pro-natalist contexts obstetric fistula may be seen as a proxy for reproductive failure, leading to the loss of social status, economic instability, individual experiences of "role failure," and ultimately stigmatization, which works to uphold the status quo (Caldwell and Caldwell 1990; Miall 1985; Jiggins 1994; Inhorn 2004; Whiteford and Gonzalez 1995).

Because fistula and its consequences are not experienced within a vacuum, the common formula employed to discuss fistula-stigma (whereby women contract fistula, deviate from social norms and expectations because they leak and smell, and thus experience social stigma which leads to the loss of social value and social discretization) fails to identify the process through which social identities are negotiated and the context within such negotiations are situated. To what extent is fistula a special condition of exclusion, privileged beyond myriad physical and psychological dissimilarities present (but not stigmatized) within a woman's community? Why is fistula a difference that is feared or stigmatized while other differences are not? In whose interest is the application of fistula stigma? How does fistula-stigma manifest and transform through a woman's life? These questions are not adequately answered in the extant corpus of

fistula literature; however, they are integral to understanding the lived experience of fistula-stigma and thus require thorough examination. My research attempts to offer such insights.

10.2 Measuring Fistula-Stigma

As women's experiences with stigma are not monolithic but are multidimensional and varied, measuring "stigma" (which has no local language translation) during this research was a complicated and imprecise task. Through preliminary interviews and an iterative attempt to modify proxy measurements, I eventually operationalized 'stigma' as an umbrella concept encompassing synergistic relationships between attitudinal and behavioral components, including social isolation, physical exclusion, verbal and nonverbal mistreatment, financial insecurity, and subjective experiences of shame, uselessness, fear, and identity loss. These proxy measurements were derived both from my preliminary research and from existent literature (Fife and Wright 2000; Link et al. 2004).

Defining the Cultural Domain of Fistula-Stigma

In order to understand fistula-stigma specifically, it was essential that I clarified the cultural domain of stigma generally. To ensure that my definition of stigma drew from local typologies and conceptualizations, I conducted two focus groups—one with men and another with women with fistula—on the topic of highly feared and socially denigrated sicknesses and conditions. Participants were asked open-ended questions regarding the "worst" conditions in their communities for which individuals with these conditions might be treated poorly, feared, mocked, or avoided. From the list of sicknesses and conditions generated from these focus groups, participants were then asked to free-list words or phrases associated with the eight conditions which were most commonly discussed (including HIV/AIDS, tuberculosis, mental illness, epilepsy, venereal disease [sometimes understood simply as gonorrhea], leprosy, polio,

and fistula) to generate a preliminary list of salient independent variables statistically correlated with stigma. In addition, because according to academic literature (as well as media and donor discourse), fistula is often said to stigmatize women due to the resultant infertility, or because women with fistula are often said to resort to prostitution, I added the two non-illness categories of ‘childlessness’ and ‘prostitution’ to the list of eight illnesses.

I asked fifty men and women with and without fistula nine questions about each of these eight conditions (plus the two non-illness categories of childlessness and prostitution) in order to compare across categories etic (or external) views of stigma. The questions covered various etic domains of stigma for each of these eight conditions, including verbal abuse, fear of contagion, and social isolation (see Table 10.1). A positive response for each question was marked as one point, resulting in nine total points for each of the ten illness and non-illness categories. (For survey, see Appendix A).

Do people avoid this category of people?
Do people refuse to eat with them?
Do people refuse to talk with them?
Do people refuse to shake their hands or touch them?
Do people mock them, gossip about them, or disparage them?
Do people fear catching their illness?
Do people avoid their children?
Do people feel disgust for them?
Will people marry them?

Table 10.1: The nine questions asked about each of the eight listed conditions and two non-illness conditions including HIV/AIDS, tuberculosis, prostitution, mental illness, epilepsy, venereal disease, leprosy, polio, fistula, and childlessness/infertility/sterility. For a complete list of the conditions and questions, see Appendix A.

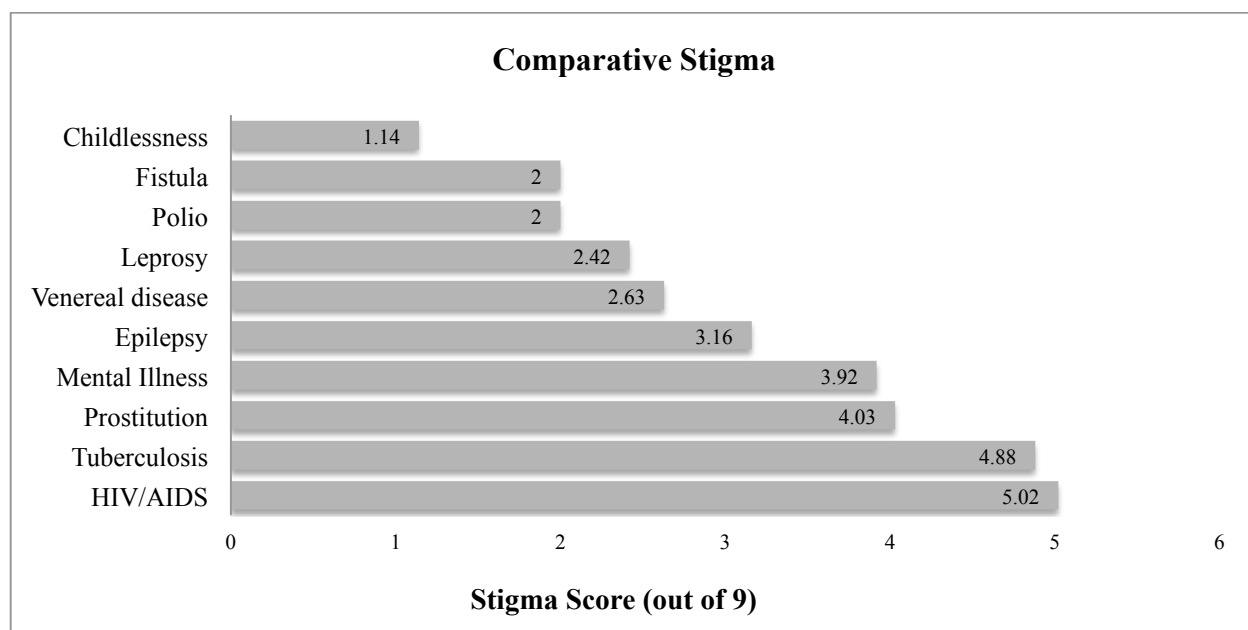


Figure 10.1: Results of the 50 Comparative Stigma questionnaires distributed to 20 men, 15 women with fistula, and 15 women without fistula. Childlessness and fistula were ranked as the least stigmatizing, while HIV/AIDS and tuberculosis were ranked as the most stigmatizing.

Of the fifty surveys completed, HIV/AIDS and tuberculosis consistently received the highest average scores (5.02 and 4.88 out of a possible score of 9), followed by prostitution (4.03), mental illness (3.92), epilepsy (3.16), venereal disease (2.63), leprosy (2.42), polio (2.00), fistula (2.00), and childlessness (1.14).

Although this exercise opened a fruitful dialogue about illness, social treatment, and perceived etiology, the questionnaire assumed that stigma for all of the illnesses/ conditions/ occupations would manifest identically. This exercise highlighted that stigma is highly variable, and that a “cultural domain of stigma” does not exist. Some questions included in the questionnaire, such as those measuring contagion, were particularly problematic. For example, tuberculosis, with the second highest stigma rating, did not appear to take on the symbolic meanings typically associated with highly stigmatized illnesses (such as moralizing discourse or supernatural etiologies); however, it was consistently ranked highly due to the perceived threat of contagion. In this questionnaire, concepts of avoidance due to perceived contagion are markers

of stigma; however, as is the case with tuberculosis, positive responses to these questions may also demonstrate appropriate public health strategies employed by friends and family members of an ill person in order to reduce the likelihood of disease spread.

Conversely, although epileptic seizures were thought among many respondents to result from a dangerous spirit possession of the body, epilepsy did not rank as highly as mental illness, prostitution, tuberculosis, or HIV/AIDS. People with epilepsy were not routinely avoided, however, during a seizure most respondents believed that the person should not be approached or touched, and after the affected person regained consciousness, the majority of respondents believed that area where s/he fallen had to be thoroughly burned. If this prescribed protocol was not followed, the most respondents believed that if another person unwittingly walked on the unburned area, s/he would be susceptible to spirit possession.

Interestingly, fistula and childlessness consistently received the lowest comparative stigma scores (both among women and men). Discussions surrounding fistula and sterility evoked words such as “pity,” “God’s will,” and “patience.” None of the respondents attributed any responsibility to women who were childless or women who developed fistula. That said, many respondents agreed that both fistula and infertility would make a woman a poor candidate for marriage.

This exercise demonstrated the difficulty in operationalizing and measuring stigma, for which stigma proxies are often difficult to disentangle from concepts that may initially appear related to stigma, but ultimately prove unrelated (such as avoidance of touch as a strategy to reduce disease spread). Interestingly, while avoidance of touch (for example) may demonstrate a rational/pragmatic strategy for disease containment for an illness such as tuberculosis, the meaning differs when the illness is not contagious (as is the case, for example, with

childlessness). Thus, a negative response to the question “Would you shake the hand of someone with tuberculosis?” would not necessarily be interpreted as a marker of stigma, while a negative response to the same question about childlessness would. My questionnaire did not control for these differences in meanings. Ultimately, this exercise highlighted the importance of specifically crafted proxy measurements for each illness/condition/occupation and aided in the construction of fistula-stigma specific proxy measurements. It underscores the importance of leaving behind a static concept of “stigma,” and rather discuss the social consequences of fistula specifically.

Defining and Measuring Fistula-Stigma through Proxies

In an attempt to standardize measurements of fistula-stigma across my sample, in addition to in-depth interviews covering similar topics, I also integrated two scales developed cross-culturally to measure stigma: the Participation Scale which measures perceptions of limitations in social participation (van Brakel et al. 2006) and the HIV/AIDS Stigma Instrument, or HASI-P, which uses proxy measurements of verbal abuse, negative self-perception, social isolation, fear of contagion, health care neglect, and workplace stigma to measure stigma (Holzemer et al. 2007). I triangulated this with data derived from preliminary fieldwork, the comparative stigma survey, and exploratory in-depth interviews.

Drawing heavily from the HASI-P (Holzemer et al. 2007, 1012), (and less so from the Participation Scale), I crafted a standardized survey of 18 questions, testing both emic/ internal and etic/external experiences of stigma (see Appendix B). The survey covered negative self-perception (a negative evaluation of self due to fistula; seven questions), verbal abuse (verbal behavior intended to harm the woman with fistula such as ridicule, insults, blame; five questions), fear of contagion (behaviors which demonstrate a fear of contact with the woman

with fistula; three questions), and social isolation (the deliberate limitation of social contact with the woman with fistula and/or breaking off relationships with her; three questions). Although the HASI-P also measures workplace stigma (barring access to employment/work opportunities based on illness) and health care neglect (offering an individual less care than is expected, or limiting access, because of illness in a healthcare setting), I did not include these categories in the fistula-stigma questionnaire (as only one of the women in my sample worked outside the home, and although women did have negative health care experiences, the questions were not relevant to women's experiences).

Of the 26 questions in the HASI-P covering these four domains, I selected the fourteen most relevant questions to the fistula experience. One question was altered in order to fit the experience of fistula: "I was asked to leave because I was coughing" was adapted to "Someone asked me to leave because of my smell." Four additional questions were added to address fistula-specific concerns which arose as salient themes during preliminary fieldwork, the comparative stigma survey, and exploratory interviews: "I feared that others would look at me to see if I was wet," "I felt useless," "I was afraid someone would judge me or gossip about me," and "I felt that I could not go to ceremonies or community celebrations" (for a complete list of questions, see Table 10.2). As the research progressed, I constructed an adapted standardized fistula-stigma survey which I believe more accurately measures fistula-stigma and fistula experience (see Appendix C). However, I continued to use the initial 18-question survey so that all 100 women's responses would be comparable.

I administered this standardized survey of 18 questions to all 100 women in my sample (typically before concluding their in-depth interview) in order to measure both external (etic) and internal (emic) stigma (or as Goffman categorized them, *discredited*, whereby an individual's

“socially undesirable attribute” is apparent, and *discreditable*, whereby an individual attempts to conceal her “socially undesirable attribute and thus “pass”). The first set of questions focused on external stigma, investigating quotidian treatment by others (past mistreatment and avoidance behaviors such as the refusal to share a meal or verbal insult). The second set of questions focused on the internal experience of stigma, inquiring about daily internal struggles (measured through proxies such as shame, embarrassment, fear of judgment, and fear of mistreatment). Women were asked after each question about its frequency. For example, for each question, I asked: “Because of your fistula, how often did the following event happen?” Response options were “never” (scored as zero points), “once or twice” (one point), “several times” (two points), and “most of the time” (three points).

Question	Category	Score (0-3)
I feared that others would look at me to see if I was wet	Negative Self-Perception	2.23
I felt shame	Negative Self-Perception	2.01
I felt useless	Negative Self-Perception	1.85
I felt as though I brought many problems to my family	Negative Self-Perception	1.78
I felt like I am no longer a woman	Negative Self-Perception	1.77
I was afraid someone would judge me or gossip about me	Negative Self-Perception	1.43
I felt that I could no longer go to ceremonies	Negative Self-Perception	1.38
Someone told me that I had no future	Verbal abuse	0.85
Someone mocked me when I passed by	Verbal abuse	0.8
Someone told me that God was punishing me	Verbal abuse	0.53
Someone refused to eat from the same plate as me	Fear of contagion	0.49
People avoided me	Social isolation	0.49
People visited me less often	Social isolation	0.45
Someone said I was responsible for my sickness	Verbal abuse	0.4
Someone asked me to leave because of my smell	Verbal abuse	0.39
Someone refused to share the same drinking cup with me	Fear of contagion	0.28
A friend of mine refused to speak with me	Social isolation	0.16
I was asked not to touch someone’s child	Fear of contagion	0.08

Table 10.2: Results from the standardized stigma survey of 100 women with fistula, adapted from the HASI-P (Holzemer et al. 2007), indicating the stigma category and average score (between 0-3) for all 18 questions (organized in descending order from highest score to lowest).

The highest reports of stigma were for negative self-perception (1.78, average per question response out of 3 possible points) and verbal abuse (0.74). Low levels of stigma were reported for social isolation (0.37) and fear of contagion (0.28). Interestingly, the original HASI-P, used to measure HIV/AIDS-stigma, returned similar results. In their measurement of HIV/AIDS-stigma in five sub-Saharan African countries, Holzemer et al. (2007) found that highest reports of stigma were in the domains of negative self-perception (with an average of 0.95 significantly lower than my measurement for women with fistula), verbal abuse (0.65), social isolation (0.64), and fear of contagion (0.27). (Additionally, they measured workplace stigma as 0.19 and healthcare neglect as 0.15).

The seven questions measuring “negative self-perception” were categorized as measurements of internal (emic) stigma, while the eleven remaining questions measuring “verbal abuse,” “social isolation,” and “fear of contagion” were combined to measure external (etic) stigma. Scores for both internal and external were then normalized. While this instrument offers far less insight than in-depth interviews, the ability to compare between women is informative.

While 66 women (66%) reported high or very high rates of internal stigma, and 15 women reported no or low internal stigma, only 7 women reported high or very high rates of external stigma, while 76 women reported no or low external stigma. Although popular discussions of the social ramifications of stigma focus heavily on external mistreatment and tangible social consequences, I found that women’s perceptions of their lived experiences minimize the prevalence of outward mistreatment and avoidance behaviors while underscoring the personal emotional and psychological burden of the illness. Thus, it becomes important to reconsider what kind of experiences constitute fistula-related stigma, heightening our awareness of internal processes while relying less on those that are primarily external.

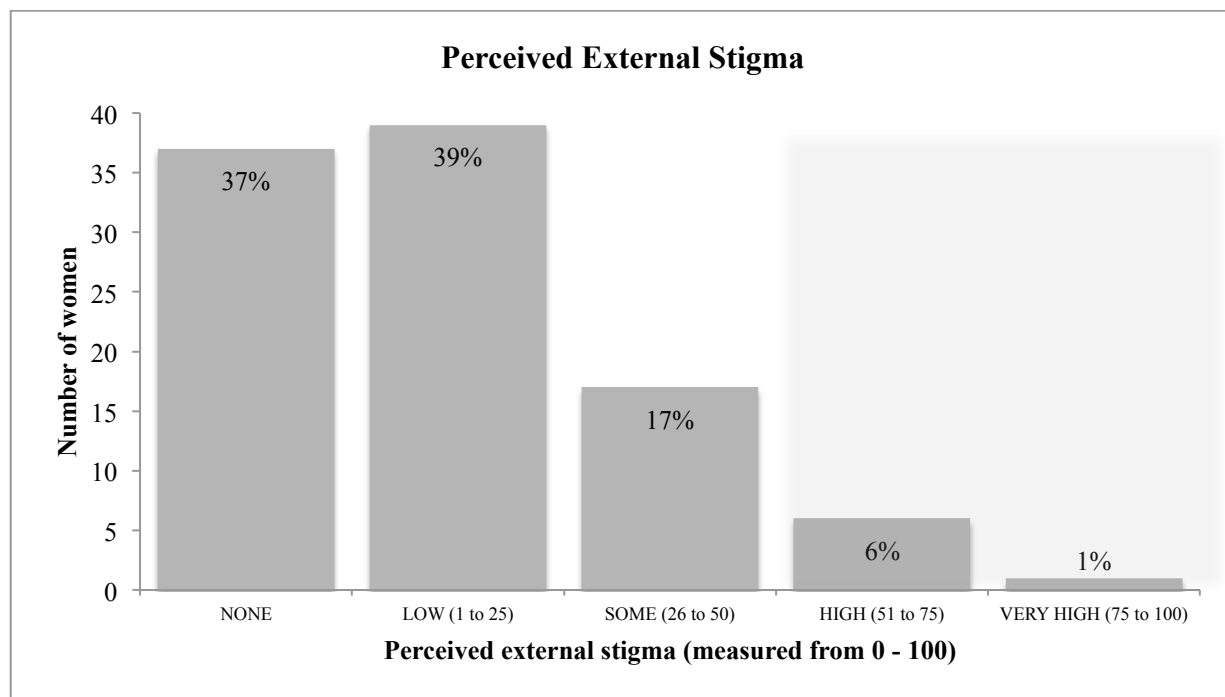


Figure 10.2: Perceived external stigma measured among 100 women with fistula, as measured through a standardized 18 question survey, aggregated into categories of “none,” “low,” “some,” “high,” and “very high.” Only 7 women reported high (between 51- 75) or very high (75—100) rates of external stigma while 76 women reported no (0—25) or low (1-25) external stigma.

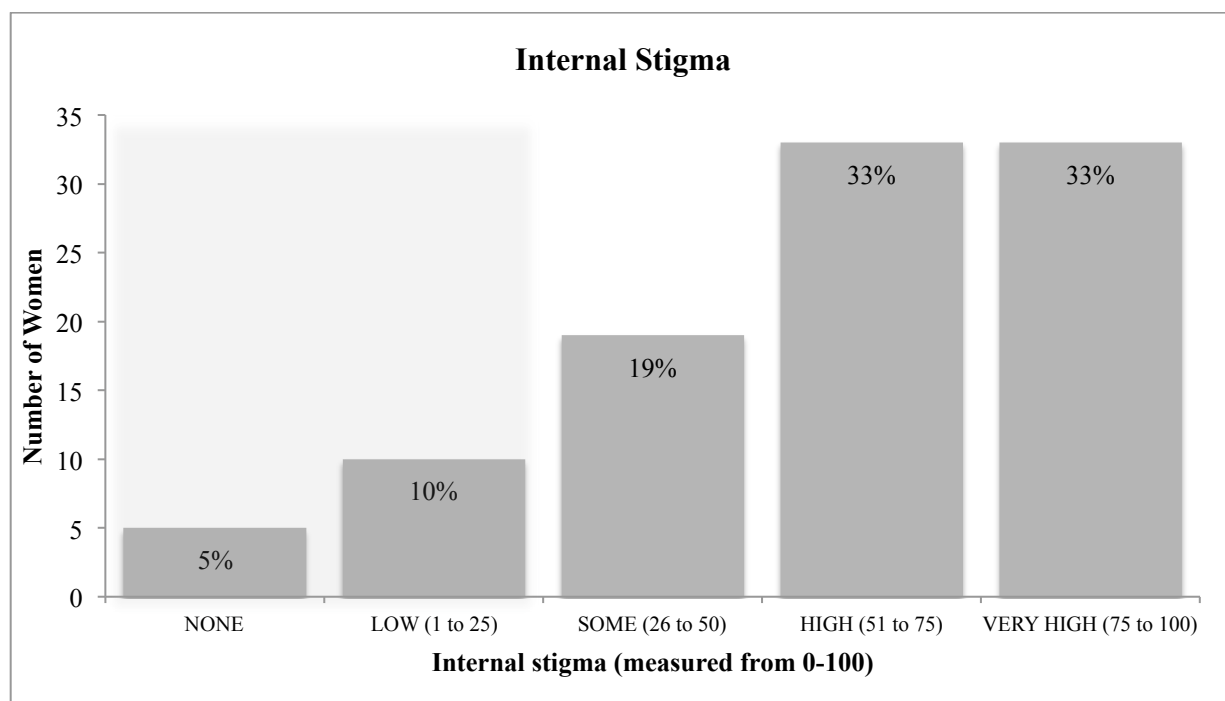


Figure 10.3: Internal stigma among 100 women with fistula, as measured through a standardized 18-question survey, aggregated into categories of “none,” “low,” “some,” “high,” and “very high.” Sixty-six women reported high (between 51- 75) or very high (75—100) rates of internal stigma, and only 15 women reported no (0—25) or low (1—25) internal stigma.

10.3 Investigating External Stigma, Drawing Insight From The Worst Cases

While the vast majority of women (76 of 100) relayed no or low external stigma, seven women reported high or very high rates of external stigma (see Figure 10.2). On a perceived external stigma scale of 0—100, these seven women averaged 65, as compared to the full sample average of 15 (the seven women’s average for internal stigma was also higher than the full sample at 76, as compared to 58) (see Table 10.3). Looking in greater depth at these seven women who reported high or very high rates of external stigma may be instructive in understanding who is most vulnerable to fistula-stigma, particularly the type of external fistula-stigma highlighted in the fistula narrative. Examining what makes these seven women different from the rest of the sample provides a deeper understanding as to why women with fistula have such diverse experiences—why for some (such as these seven women) the consequences of fistula *are* profound, affecting every aspect of women’s lives, deteriorating their social bonds and community status, exacerbating poverty, causing profound emotional distress, and diminishing their chances of finding a romantic partner—while for others, the illness is merely physical, causing anguish in the way any illness does and shame in the way one might imagine chronic incontinence would, but largely leaving their social lives untouched and their support systems intact.

	Woman 1	Woman 2	Woman 3	Woman4	Woman 5	Woman 6	Woman 7	Average	Full Sample Average	Statistical Significance of difference between groups
Perceived External Stigma (Scale: 1-100)	85	70	67	58	55	55	52	65	15	P=0.00001
Internal Stigma (Scale: 1-100)	52	76	71	62	100	95	48	76	58	P=0.19
Ethnicity	Zarma	Zarma	Songhai	Hausa	Mossi	Kanuri	Fulani			
Age	26	32	45	28	20	41	45	33.9	31.0	P=0.45
Years Living with Fistula	1	0.5	4	5	2	25	10	6.8	7.6	P=0.97
No Mother	No Mother	No Mother	Mother	Mother	No Mother	Mother	No Mother	4 of 7	18 of 100	P=0.005
Living Children	0	3	4	0	0	0	3	1.4	1.1	P=0.59
Total Pregnancies	3	6	7	2	1	1	8	4	3.7	P=0.80
Marital Status	Divorced	Separated	Divorced	Married	Separated	Divorced	Separated		See Table 7.1	P=0.18
Age at Marriage	21	15	16	14	13	13	16	15.4	15.5	P=0.97
Number of Co-Wives	1	2	2	1	0	2	2	1.4	0.76	P=0.016
Family Marriage	No	Yes	Yes	Yes	Yes	No	Yes	5 of 7	47 of 75	P=0.65
Forced Marriage	No	No	Yes	No	Yes	No	No	2 of 7	24 of 65	P=0.66
Months at fistula center	8	0.5	3	36	18	72	3	20	6	P=0.000004

Table 10.3: Selected characteristics of the seven women who reported high or very high rates of external stigma as compared to the whole sample. The only statistically significant differences between groups were: (1) if a woman had a living mother, (2) the number of co-wives a woman had, and (3) the length of time a woman spent at a fistula center. Significance was determined with an Alpha level set at $P < 0.05$ and values were calculated either with Chi-square testing or Two-tailed T-testing.

Not Statistically Significant Differences

Of the seven women who experienced the worst external stigma, the average age of marriage was 15.4 (ranging from 13 to 21), compared to the full-sample average of 15.5 (ranging from 10 to 24). The seven women represented six ethnic groups (Zarma, Songhai, Hausa, Fulani, Kanuri, and Mossi), out of the seven total ethnic groups represented in the sample (if the sample is enlarged to the eight women who experienced the highest perceived external stigma scores, then all seven ethnic categories, including Tuareg, would be represented). The average age of the seven women was 33.9 (ranging from 20 to 45), compared to my full-sample average of 31.0 (ranging from 15 to 70). The seven women had lived with fistula for an average of 6.8

years (ranging from 6 months to 25 years), compared to the full sample average of 7.6 years (ranging from 2 months to 50 years).

The seven women had an average of 1.4 living children (ranging from 0 to 4, where 57%, or 4 women, had no living children), compared to the full sample average of 1.1 living children (ranging from 0 to 6, where 55%, or 55 women, had no living children). The seven women had an average of 4 pregnancies each (ranging from 1 to 8), compared to the full sample average of 3.7 (ranging from 0 to 12 pregnancies).

Another noteworthy variable was marital status. Of the seven women, three (42.9%) were divorced, three (42.9%) were separated, and only one (14.3%) was married. In the full sample, 23% of women were divorced, 36% were separated, 3% were widowed, and 38% percent were married (see chapter seven). When marital status between the two groups is calculated in a Chi-square test, the result does not reach significance ($p=0.18$). However, the one woman in the sample of seven women who was married had previously been divorced by her first husband because of her fistula. If she were counted as divorced, the Chi-square test would just reach significance ($p=0.04$). It is unsurprising that of the women who recounted the most severe experiences of external stigma. Only one remained married (as being outside of a marital union among women in Niger is aberrant and socially disparaged). However, the causal relationships driving the deviation from the sample norms cannot be explained by the quantitative data.

Significant Differences

Although quantizing marital information (such as number of co-wives and rank) is highly problematic (as it overlooks important life events such as divorce, the timing of taking co-wives, or multiple marriages over a life-time), it may still be useful to note that among the seven

women, there was an average of 1.4 co-wives per woman,⁹² compared to a full-sample average of 0.76 co-wives. This difference was statistically significant at $p=0.016$. While this relationship is interesting, a causal relationship cannot be proven from the statistics. It may be the case that having more co-wives leads to higher stigma (as co-wives may complicate a woman's ability to conceal her fistula and may put pressure on husbands to divorce wives with fistula); however, it is also plausible that poorer community reception, fewer community ties, and less social status within the community (all factors leading to higher fistula-related stigma) encourage husbands to remarry more wives more quickly following the development of a woman's fistula. My in-depth, qualitative research suggests that both explanations are true.

The seven women with the most severe experiences of external fistula-stigma had waited at fistula centers an average of 20 months when I initially interviewed them, compared to the sample average of 6 months, a highly significant difference at $p=0.000004$. These data suggest that either higher rates of external stigma at home encourage women to leave hostile living circumstances and find respite at centers, or that prolonged absences from homes and communities while women seek biomedical treatment have negative effects on women's social lives and potentially increase fistula-related stigma. Again, while the quantitative data cannot indicate causality, my qualitative data suggests that both explanations may have merit.

Finally, I posit that the power of one social fact, the presence of a mother as a protective figure, to predict external fistula-related stigma exceeds any other predictor. In rural Niger, a mother's protection, support, and love insulate women from destructive social dynamics. Indeed, biological mothers (and not necessarily families) prove to be a woman's strongest defender and advocate. Women with fistula who live with their mothers tend to experience shame but little to no mistreatment or external stigma. Motherless girls and women,

⁹² One woman had no co-wife, two women had one co-wife, and four women had two co-wives.

however, are married significantly earlier than their peers, are left vulnerable to destructive intra-household and community politics, and suffer from more negligence and withholding of medical care—laboring significantly longer at home before being taken to a health clinic.

Without the Protection of a Mother

From both a qualitative and quantitative perspective, it appears that women who have lost their mothers (due to death, migration, divorce, or abandonment) have experienced the greatest degree of external social stigma.⁹³ Of the seven women who reported the highest rates of external stigma, four (or 57%) did not have mothers active in their lives (due to the untimely death of their mothers, divorce, or marital separation). Of the remaining 93 women (with moderate to low or no external stigma), only 14 women (15%) grew up without mothers.⁹⁴ Women who reported the highest levels of external stigma were significantly more likely to not have mothers than the remaining women in the sample ($p=0.005$). The qualitative data reinforce these findings.

Age of Marriage for Motherless Girls

Many women who were raised away from their mothers were married earlier than their peers. In my sample, of the 18 women who had no mother at the time of their marriage, women were married at an average of 14.3 years (± 2.8), compared to the remaining 79 women who were

⁹³ Additionally, women who lived with their mothers and stepfathers (in the case where parents divorced and then mothers remarried) also reported higher rates of mistreatment than women who lived with their mothers and fathers, indicating (not surprisingly) that when children are not raised within supportive family environments, they are more susceptible to mistreatment in the face of illness. Hagera, a fifty-year-old Songhai woman believed that she experienced mistreatment at home because she lived with her stepfather and her mother's co-wives. She said, "It isn't at my father's house that I live, but my stepfather. If he were my father, maybe this mistreatment wouldn't have happened."

⁹⁴ Five older women had recently lost their mothers due to older age and were excluded from the calculation. Additionally, some women did not grow up with their mothers active in their lives due to divorce; however, because custody can be fluid, and girl-children often move between households, only women who were "motherless" due to death were included in calculations.

married at an average of 15.7 years (± 2.5).⁹⁵ Using an unpaired 2-tail t-test, the age of marriage for women without mothers is significantly less than the age of marriage for women with mothers ($p=0.042$).

Hasana, a twenty-seven-year-old woman who had lived at a fistula center for two years when I met her, had lost her mother due to complications during the birth of her younger brother when she was a young girl. Hasana was sent to live with her paternal aunt, and was married against her will at 11 years old. She believed that, “It was because my mom was dead that I was married so early—it would never have happened if she was there.”

When her parents divorced when she was just learning to walk, Tandahamed, a thirty-seven-year-old Tuareg woman, was sent to live with her paternal aunt.⁹⁶ She says that she was forced to marry a neighbor at the age of fifteen. Tandahamed lamented, “I didn’t love him. I tried to refuse him, but at that time I was living with my aunt, and she said that if I didn’t marry him, I would no longer be allowed to stay at her house. For her, it was time for me to leave her house. She was tired of caring for me.” Tandahamed believed that her aunt considered her a drain of resources and saw marrying her off as an easy way to rid herself of the responsibility of raising her.

The Protection of Mothers

Many women attributed the lack of community gossip or social mistreatment to the respect for their mothers. One mother who was accompanying her thirty-four-year-old daughter to the fistula center explained, “In our village and almost all of the villages, a mother is the only

⁹⁵ Three women were left out of the statistical calculation because they could not estimate their age at marriage.

⁹⁶ Although for quantitative calculations, I only included women who were “motherless” due to death, many women experienced similar losses of maternal protection due to divorce and child custody practices that consider children the property of fathers rather than mothers. Children are either left to the care of their father’s remaining wives, or sent to live with (typically paternal) grandmothers or aunts.

one who will never be disgusted by her daughter.” “No, never!” she repeated emphatically.

Mothers often protect their daughters not only from intra-household politics, but within the larger community as well. As Maimouna, a thirty-two-year-old Zarma woman whose mother passed away when she was a child, said, “If your mother is there, people won't talk about you. But if she's not there, they have no shame, they will say anything.” Similarly, Dommo, a fifty-two-year-old Zarma woman with fistula explained to me, “No one treated me badly. You understand, since I had gotten the sickness I was with my mother.” Dommo elaborated, “Before my mom died, I had become an adult, I had become in charge of myself. If you have a mother, you can't suffer... But really, if you don't have a mother and you get this sickness, you will really suffer.”

Maimouna and Dommo, speaking of how motherless girls and women are unprotected from gossip, community mistreatment, and suffering, perfectly described twenty-seven-year-old Hasana (who is quoted above). After Hasana developed a fistula, Hasana lived with her aunt, who did not take proper care of her, who withheld access to treatment from her, and who disrespected Hasana in such a public way that other people in the community began to adopt similar behaviors:

She was disgusted by me. She didn't take care of me. But it was my aunt who raised me, so I couldn't leave her house. I spent one year with fistula before going to the hospital... Because my mother was dead. If my mother were there, she would have brought me to the hospital. But my aunt refused to accompany me to the hospital. My aunt said that she wouldn't give me money for transportation. Before I got sick, I did everything at my aunt's house, but when I got sick, I couldn't cook or clean and my aunt didn't want me around anymore... Even others knew how my aunt treated me, so they did it too. My friends were disgusted and they ran from me.

Generally, I found that women who lived beyond the watch of their mothers had very different relationships to their families. For example, women who lived only with their fathers and his co-wives recounted stories of mistreatment and the lack of financial support. Saouda,

one of the seven women with fistula who scored highest in external stigma, and whose mother died when she was young, told me:

Even as a child my mother's co-wife hated me. She'd tell me that every bite of food I took was a bite taken from her own children's mouths. When I got fistula, things were much worse. She was very happy that I became ill. When she prepared food, she'd never give me any. I was always hungry. She ridiculed me. She told everyone in the village about my illness. She wanted me gone.

Hasana, a twenty-year-old Mossi woman whose mother died while birthing her younger sibling, had a similarly negative relationship with her stepmother. Like Saouda, Hasana was also one of the seven women with the highest external stigma scores. When I asked Hasana why she believed she experienced so much more mistreatment than other women with fistula, she asked me, "Without the protection of a mother, who would protect me?" "No one would protect me," she answered. Hasana believed that had her mother been alive she would have been protected from the worst mistreatment following the development of her fistula, much of which came directly from her natal household, the worst of which came directly from her father and stepmother.⁹⁷ She explained, "Some people in the village say 'it's because your mother is not alive that your father and stepmother treat you like this'." Hasana also believed that having a mother would have protected her from both mistreatment and also from the negligence and lack of care that kept her from receiving appropriate medical care during her labor in the first place:

My mom died during the delivery of the child she had after me. It was God's destiny for her. It happened during a long labor and she wasn't taken to a hospital soon enough. She was given local medicines to drink, and told that these teas would help move the baby in the proper position, and help the baby to come out quickly. People kept saying that today she would deliver, by giving her the local medicine. But then one day, two days, three

⁹⁷ The relationship between fathers and daughters can be as complex in Niger in the context of divorce. Men often spend very little time at home and relationships between co-wives can be messy, riddled with jealousy and resentment. Co-wives are often engaged in a silent but strategic war, which can battle on for decades over scarce resources, status, and a husband's preference. When disputes between co-wives erupt (or myriad other conjugal problems), divorce or separation is common. When women leave their husband's home, they are obligated to leave behind their children. If a young woman's mother is gone, and she is left living with her father, he is often rather removed from her quotidian care but his remaining wives often lobby for him to send the girl away to live with a relative elsewhere (to avoid competing with her children for resources).

days, would pass. Soon, four days had passed that she was in labor in the village. She still hadn't delivered, and she started hemorrhaging. It was only when she started losing blood that they decided to bring her to the hospital... But they hadn't even arrived at the hospital when she died. She died on the road...

If my mom were alive at this moment, I wouldn't be here... I wouldn't be here because one's mom is the one who takes care of the children. The father doesn't take care of them. He's just a father. And if the mom is not alive, he doesn't care for them... If my mom were alive, even with the sickness that I had, she would be with me, accompany me to the hospital... If my mom were alive, I would not be here like this. And wherever I would be, I would be with her, because of my sickness. Whatever is the situation, a mother does not throw out her children, but a father will.

Hasana's case illuminates the unseen and unspoken costs of maternal mortality, the young children left behind, motherless, and vulnerable, left without advocates. These children, particularly girls, are left more vulnerable to maternal risk themselves—often raised by duty-bound stepmothers or aunts, motherless girls are considered competition for scarce household resources, seen to be taking food from their step-siblings' or cousins' bowls and clothing from their backs, and thus are married off earlier.

During labor, motherless girls are less likely to have an advocate in the household who, in the case of obstetric complications, lobbies to move her more quickly to a health center. Motherless girls and women are more likely to labor at home longer as household members wait to see if the complication will resolve on its own. Hasana was left to labor at home three days before being taken to a health center to deliver on the fourth day.

Of the 18 women who had no mothers at the time of their labors that caused fistula, these women labored at home for an average of 2.3 days before accessing care at a health clinic (laboring for a total of 3.1 days). This can be compared to the remaining sample of women who labored for 1.6 days at home, and 3.1 days total. While the women without mothers labored for the exact same amount of total time, they were kept home for an average of fifteen hours longer than their counterparts (this is significant at $p=0.016$). The eighteen women without mothers in

my sample spent an average of 70% of their labors at home, and 32% of these women spent their entire labors at home, never seeking care at a biomedical health center, as compared to the remaining sample who spent 51% of their labors at home, and only 13% spent their entire labors at home.⁹⁸ Indeed, women without mothers were significantly more likely to labor entirely at home (without ever visiting a health clinic) than women with living mothers ($p=0.031$). So, the cycle of maternal mortality and morbidity continues, and children like Hasana whose mothers died from maternal-related causes, and who are left without advocates in the household, to labor longer without access to medical care, may be more likely to be the victims of obstetric catastrophe themselves.

The Complex Role of Families and Cousin Marriages

Before conducting this research I hypothesized that factors such as severity and duration of illness, number of living children, age at the contraction of the fistula, and seniority among co-wives would largely determine the degree to which women are exposed to fistula-related social stigma. But there is one factor that I had not initially considered—the complex role of the family.

At first glance, families appeared to be the most important line of defense for women against fistula's negative social consequences. Talata, a Hausa woman in her later 60s who had lived with fistula for at least 20 years, explained that because of fistula, “husbands divorce their wives, but families stay with her.” Women told me again and again how one's family does not abandon one of its own, sticking with her even if her husband or friends have not. Indeed, tucked away in the heart of the household, women with fistula often took refuge among their extended families.

⁹⁸ For a more in-depth discussion of labor lengths and the amount of time spent in homes versus clinics, see chapter nine.

While most women had little experience being openly ridiculed or mistreated, one explanation for this could be because the majority of women practiced strict self-regulation, frequently avoiding leaving their homes, and carefully managing who knows about their condition—often keeping it a secret from everyone in the community except their closest family members (as will be discussed in chapter twelve). But, the dynamics of families are rarely clear-cut, particularly in places that practice polygyny.

The preferred marriage in Niger is between first cousins.⁹⁹ Many women in Niger are married to their first cousins, transforming the powerful relationship between nieces and aunts (whereby an aunt is often referred to as ‘mother’) into a fraught relationship between a bride and mother-in-law. In the case of cousin-marriages, I found that sides become blurred and allegiances messy when a woman develops fistula. As an aunt, a woman probably would have taken her niece’s side, cared for her, acted as her second mother, kept her secret, and protected her from fistula-stigma and community mistreatment. But as a mother-in-law, her primary concern is her son and his interests such as producing offspring—which might mean that she gossips about her niece-cum-daughter-in-law, belittles her, and pressures her son to leave her for a woman who might more easily bear her grandchildren.¹⁰⁰ Yet, she is still the woman’s aunt, and thus still privy to the information and access of any other close family member, making “the family” feel a little less safe.

Salamatou, a twenty-eight-year-old Hausa woman married to her maternal first cousin, explained to me that after the development of her fistula, she returned home to her husband’s

⁹⁹ As discussed in chapter seven, 45% of women were married to members of their family, most commonly cousins (some maternal cousins, some paternal, and most ranging between first, second, and third cousins). Many women in my sample believed that family marriages offered the most stable marriages.

¹⁰⁰ It is important to note however, that this is a generalization. Mothers-in-law sometimes act as advocates for their daughters-in-law (regardless of familial relationships), encouraging their sons to be patient and support their wives through the illness. In some cases, mothers-in-law even accompanied their daughters-in-law to fistula treatment centers.

house, but that his parents were opposed to her being there, “They asked him ‘Why would you bring her home, a woman like that, a woman who has this sickness?’ He said, ‘No, I brought this woman to my house when she was in good health, so I cannot send her away now.’ They said ‘Do not bring that woman back!’ They did everything to change his mind. Because of them, his demeanor (*fuska*) changed, and he sent me away.”

This tension created by family marriages is apparent in the interaction of Binta, a thirty-year-old Hausa woman who contracted fistula five months before following her fifth pregnancy, and her mother Ju'mai. Binta sat under a tree on the clinic grounds next to her mother. Binta still couldn't walk due to nerve damage during her labor. One afternoon, I sat with Binta and Ju'mai as Binta explained to me the difficulty in navigating her marriage to her first cousin, and the tension that this marital disharmony had brought between her and her aunt. The friction between mother and daughter were apparent, where Ju'mai was torn between her allegiances to her daughter and her sister and nephew:

Binta: My mother-in-law always gives me problems. She didn't help at all when I was sick.

Ju'mai: You shouldn't talk like that!

Binta: Well, it is true. She didn't come and see me when I was sick. She didn't even send money. Neither did my husband. He has not said anything. He has not given me money. He never even gave his condolences for the baby.

Ju'mai: Still, you shouldn't say these things.

Ali: Ju'mai, why haven't you stepped in and spoken to your sister about the way he is treating Binta?

Ju'mai: What can I do? He is my nephew...

Binta: I didn't want this marriage. Only my mother wanted it. She wanted the marriage, and now that I'm sick, he hasn't done anything to help me.

Ju'mai: Binta, everyone has his own way of acting. [Said to me] Maybe he thinks that she will never be healed.

Ali: Is that enough reason to treat her poorly?

Ju'mai: Well, if it wasn't that, then why? Before he was nice, he was a good man.

It was only when Binta got sick that things changed. Even between the tongue and the teeth, one day they will fight, no?¹⁰¹

Binta: If someone is with you, if they do things for you. If they get you water,

¹⁰¹ A Hausa proverb indicating that even those who are closest to one another will once in a while have disagreements.

wash your clothing, they prepare your meals, then why would you neglect them when they get sick? When we were leaving to go to the hospital, my husband, who works at the market near the car station, saw us. He didn't say goodbye. He pretended not to see us. He pretended not to see!

Ali: Binta, if you are healed, will you ask for a divorce?

Binta: Yes.

Ju'mai: No! You shouldn't even say the word divorce (*rabuwa*)!

As demonstrated in this conversation between mother and daughter, while cousin marriages can be protective, offering increased marital stability and the consolidation of alliances, family marriages also can introduce novel complexities and conflicting interests. In the case of Binta's illness, her aunt-cum-mother-in-law, who remained close to her older sister (Ju'mai), had unfettered access to information about Binta's health, but had used that privileged position as a family insider to encourage her son to disinvest from his marriage with Binta and begin looking for a new wife.

10.4 Internal Stigma: Experiences of Shame, Uselessness, and Loss of Identity

Focusing on the internal psycho-emotional processes of women with birthing injuries in Tanzania, Mselle et al. (2011) describe that at the core of the fistula experience is a "deep sense of loss." Mselle and colleagues' description of the impacts of fistula on women's lives closely mirror my own findings. Rather than focusing on the behaviors of "stigmatizers," or outward mistreatment, Mselle et al. instead focus on the heavy emotional burden fistula causes women, specifically identifying four types of loss: (1) loss of body control: smell, wounds, pain and discomfort; (2) loss of the social roles as woman and wife: shattered sex life, inability to attend to daily commitments; (3) loss of integration in social life: disrupted marriages, disrupted social life; (4) loss of dignity and self-worth: dependency, uselessness, and self-contempt. Considering how few women in my sample experienced external fistula-stigma (only 7 women experienced high or very high rates), in contrast to the 66 women who reported high or very high rates of internal stigma (while only 15 women reported no or low internal stigma) (see Figure 10.2 and

10.3), Mselle and colleagues' prioritization of the emotional internal taxation caused by fistula, is in alignment with my own findings. In particular, women I spoke with highlighted experiences of shame, ruined identity, and uselessness, which I argue are the primary components of internal fistula-stigma.

The Ubiquity of Shame

Shame is a particularly prominent feature in the lives of women in Niger, mediating most interactions women have, as well as impacting women's sexuality and reproductive health. Among the Hausa of Niger (and Nigeria), *kunya*, or shame (also translated as deference, modesty, or respectful avoidance), plays an important role in quotidian life. Similarly, the Zarma ethnic group's relationship to *hawī* (shame) dictates the boundaries and exigencies of relationships and social constraints on personal conduct. The Fulani of Niger have an analogous relationship to shame, or *semteende*, an integral component of *pulaaku*, or "Fulaniness." For women in Niger, *kunya* (or *hawī* or *semteende*) is a way of life. Pierce (2007) highlights the importance and ubiquity of *kunya* among the Hausa:

Kunya means "shame" or "modesty" and is a very desirable quality, particularly among subordinate people, the young, and especially young woman. Kunya is an emotion one feels toward people with whom one has a relationship of respect, and it causes one to avoid looking at them directly, using their given names, or speaking familiarly... Having kunya also, critically, leads one to avoid broaching inappropriate topics. Sexual conduct—and particularly improper sorts of sexual conduct—is such a topic. Being a modest, appropriate, well-mannered person more or less ensures observing general norms of secrecy (551-552).

Expected to deliver alone and completely unassisted, I asked Nana, a fifteen-year-old Hausa woman with fistula, who had taught her what to do and expect during childbirth. She covered her face, embarrassed, and shook her head: "No one." She and other women suggested that such a conversation between mother and daughter would be too shameful. A young woman's first pregnancy—while cause for later celebration—is so shrouded in shame because it

is visible evidence of her sexual maturity that it goes unacknowledged, which has many consequences for seeking prenatal care or timely obstetric interventions (Wall 1998). “*Ta cin wake*,” “She ate beans,” Hausa people say euphemistically, avoiding the shameful recognition that a young woman has become sexually active. When in labor, she may avoid calling for help or alerting her family.

Nana, the fifteen-year-old Hausa woman explained that, “if you cry during labor, and then you play with your child later, giving him kisses and holding him, you will feel *kunya*.” When her child is born, a woman may avoid calling him or her by name out of shame. A mother’s relationship with her first child will always be characterized by respectful avoidance. According to the famous biography written about a Hausa woman in 1950s Nigeria, Baba of Karo: “the mother refuses to look at him [her first child], she refuses to touch him, she hides her hands and covers her head and face. It is her first child, she is very embarrassed . . . The child’s mother always remains ashamed of him” (M. Smith 1955:139—140).

Saying the name of one’s husband out loud brings a woman shame. As Nana explained, “You don’t say the name of your husband. You don’t say the name of your parents, and you never say the name of your in-laws. If you say the name of your mother-in-law or father-in-law out loud, there is so much *kunya*. When you die, it will be all black. There will be no light, no heaven. If you respect your parents, you never say their names.” Indeed, according to Nana, articulating the name of one’s in-laws is such a transgression of appropriate behavior that it not only brings shame, but also may interfere with a woman’s eventual ascent to heaven.

Twenty-six-year-old Binta explained that shame was an integral part of rural people’s behavior, “It is the character of people of the bush to have shame. It is just their behavior. Every day, every day, they always feel shame.” I asked 55-year old Oumou about what causes *kunya*,

and she began to enumerate a long list behaviors culturally deemed inappropriate, immodest, or disrespectful. I asked her if both men and women experience *kunya*, and she explained that:

Yes, they both feel it. But women feel it more. Everything men do is fine. Men can fart anywhere, for example. But women can't. They will feel overcome with shame. *Kunya* is internal—if you have your period and you stand up, you will feel shame—people will say that your wrapper is dirty. They will tell you that you need to go change. The shame is strong.

The never-ending quest to avoid *kunya* guides so much of women's daily behavior, dress, and health-seeking choices. During interviews, in cool and measured voices, women walked me through the obstetric catastrophes that caused their injuries. Thirty-two year-old Aisha recounted the five-day labor that caused her fistula. She remembered the half-delivered child, his gruesome extraction, and the constant flow of fecal matter she discovered upon waking from a two-week coma. She didn't cry; she didn't wince. I asked my research assistant, Ramatou, how she could relate such loss, pain, and trauma with such a perfected poker face. Ramatou explained that the shame an emotional reaction would bring her would be nearly as bad as what had already happened. Although I interpret Ramatou's response as hyperbolic, the meaning is clear: it is through quotidian shows of stoicism, self-control, and fortitude that an individual can avoid shame.

Given the deeply engrained cultural importance of *kunya*, it is not surprising that the most prominent feature in the experience of fistula is no proxy measuring external stigma—neither outward mistreatment nor social abandonment, rather a profound sense of shame. Women expressed shame due to their inability to attend important ceremonies within their communities such as marriages and baptisms (although some women who were adept at concealing their incontinence did continue to attend these events). Shame because their lack of control over their basic bodily functions was so visible. Shame that those to whom they ought to be social seniors

(like children) could see the wetness they would leave behind, the wetness that would run down their legs and pool at their feet. Shame that their most intimate—most shameful—body parts were so visibly broken.

Hadiza, a sixteen-year-old Hausa woman with fistula explained that, “No one treats me poorly, but still, I feel shame. I feel *kunya* because of the urine. *Kunya* in knowing that people will notice my wetness.” Dije, a thirty-seven-year-old Hausa woman with fistula, explained that, “My husband didn’t say anything about [the fistula]. But even if he didn’t react, as a sick person, you know that you’ve changed. You don’t feel the same. You don’t have health there [in your vagina] and you feel ashamed.”

Given the deeply entrenched and embodied nature of shame, it is not surprising that the experience of fistula is most defined by personal shame. In the standardized stigma survey conducted with all 100 women in the sample, only 24 women claimed not to feel shame because of their fistula (and 4 women claimed to experience it “once or twice”) (Figure 10.4).

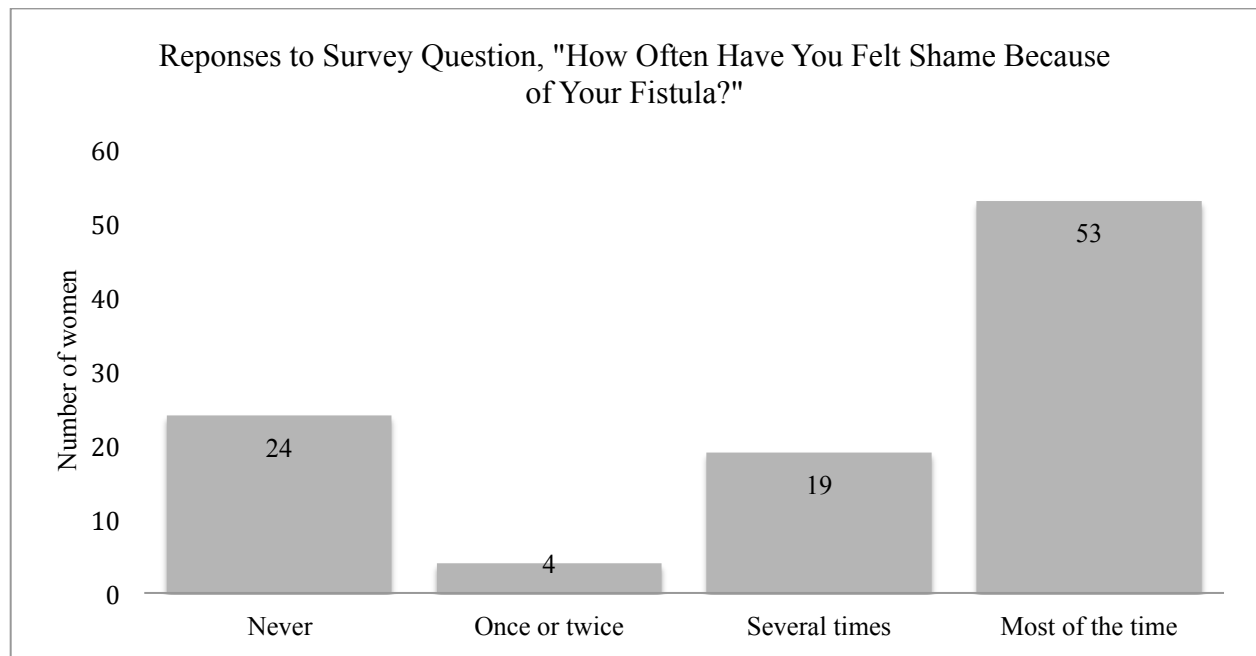


Figure 10.4: Responses of 100 women to stigma survey question asking “How often have you felt shame because of your fistula?” Twenty-four women responded “never,” 4 responded “once or twice,” 19 responded “several times,” and 53 women responded “most of the time.”

Many of these women articulated the same sentiment as twenty-six-year-old Binta, who claimed, “I did not buy this illness at the market, illness comes from God, so why feel shame?” Yet, the majority of women (53 women) expressed that they felt shame because of their fistula most of the time (and the 19 remaining women experienced shame “several times”). More than any other question on the survey, the question about personal shame elicited the most adamant agreement, with most women answering with “*kwari!*” “*sosai!*” or “*correcto!*” (very much!, so much!, correct!), rather than a simple “yes.”

Ruined Identity, Broken Vaginas

For many women, fistula changes their sense of self. Nana, a thirty-two-year-old Tuareg woman (who had successfully concealed her fistula for several years from all of her social contacts, including her husband), explained that although no one knew about her incontinence, it had profoundly affected the way she thought about herself. When I asked Nana if fistula had affected the way she thought about herself as a woman, she explained, “I accompany the women, but I am not a woman anymore.” Nana’s response—her belief that she was performing femininity, a simulacrum of the woman she once was—was shared by many women with fistula who believed that they only masqueraded as women, disqualified from the gender by their “broken” vaginas.

In the stigma survey, 70 women expressed that they had at one point or another felt as though they were no longer women because of their fistulas. For 48 women, they felt this way most of the time (see Figure 10.5).

Haju, a twenty-year-old woman who had been healed of fistula, laughed when I asked her if she continued to feel like a woman when she had fistula. “I didn’t think about being a woman,” she responded, “I didn’t even feel human!” Amina, a thirty-year-old Hausa woman

who had recently contracted fistula, explained, “I don’t even know if I can be healed of this sickness, so the question of being a woman, of beauty, it isn’t relevant.”

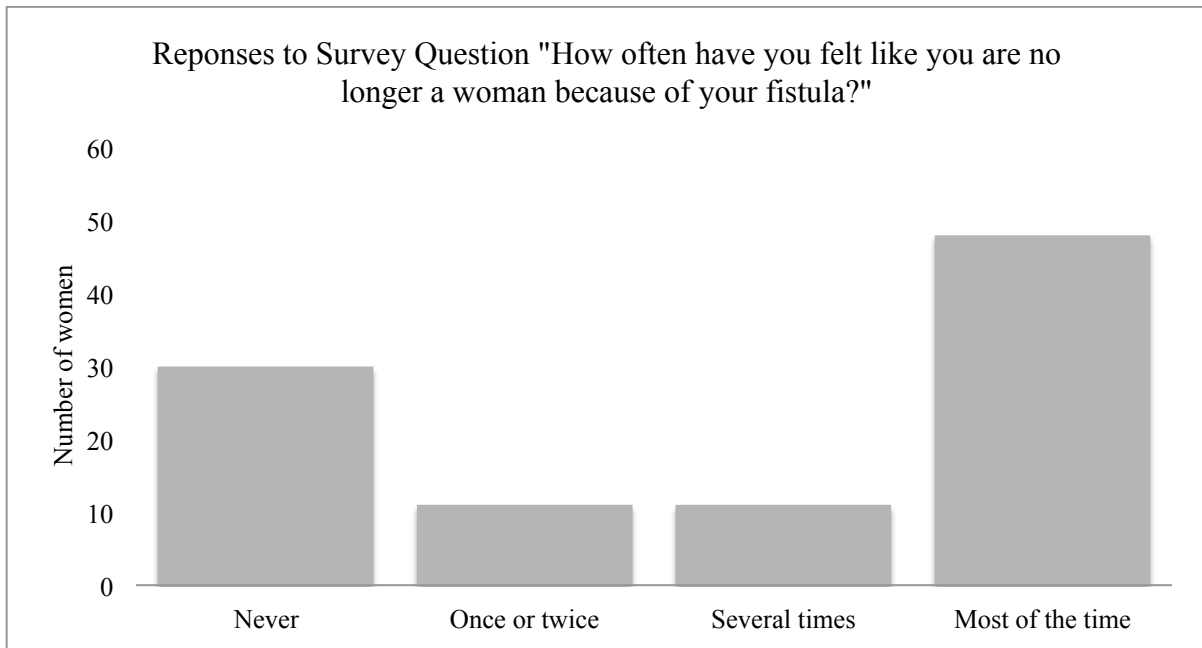


Figure 10.5: Responses of 100 women to stigma survey question asking “How often have you felt like you are no longer a woman because of your fistula.” Thirty women responded “never,” 11 responded “once or twice,” 11 responded “several times,” and 48 women responded “most of the time.”

Sahara, a twenty-four-year-old woman with fistula, explained that because of her sickness, she was no longer a woman, “If your vagina isn’t right, you can’t be a woman.” “And if you have a problem with your breasts, can you be a woman?” I asked, in order to clarify the specific requirements of “womanhood.” “Yes, you can be,” she replied. And if you are not with your husband? If you are divorced? If you cannot have children? Yes, yes, yes, she replied. Indeed, there was something specific about an illness that affected a woman’s vagina that for many women constrained their abilities to embody a woman.

Roukaya, a thirty-year-old Zarma woman laughed heartily when I asked her if she felt like she was no longer a woman because of her fistula. Roukaya had just returned to the center for a 3-month post-op check-in. After two years of incontinence, she had finally attained

continence. “I was always a woman,” she asserted, “even with the sickness. Sick or well, I will always be a woman. It is only men who think that if a woman is sick, she isn't a woman.”

Safia, a twenty-seven-year-old Kanuri woman from the Chadian border explained that because of fistula she didn't feel like a woman anymore. I asked Safia if she would become a woman again if she were healed and remarried. She explained that she would be. Interestingly, the self-conception of womanhood appears fluid rather than static, allowing for women to enter and exit multiple times throughout their lifetimes.

Fasuma, a twenty-three-year-old Fulani woman, explained that in her opinion, “a vagina makes a woman” (*gindi, shi ne mace*). Fasuma explained that “if there is no vagina, there is no value” (*in babu matuci, babu darijar*). “Because you can't give birth or have sex without a vagina, if yours is broken, you have no value as a woman. Even if a man accepts to stay with you with this sickness, it will be you who still feels uncomfortable because the sickness touches your vagina,” Fasuma added.

Without Value, Without Use

Women frequently complained that because of their fistulas, they were not able to be a productive member of their households or communities—they worried that they were no longer “useful.” These women felt that the exigencies of managing their incontinence, their physical weakness due to the injury and other co-morbidities, or the implications of their “broken vaginas” limited their abilities to contribute to their households through farming, preparation of meals or foodstuff, or collection of water or wood, and inhibited them from satisfying the needs of their husbands', both sexually, but also materially, washing his clothes, cultivating, and preparing food. Women often said that to have value (*darijar*) as a woman, one has to be useful, and if fistula makes a woman useless, then it also makes her without value.

In the stigma survey, 72 women expressed that they had at one point or another felt useless because of their fistulas. For 48 women, they felt this way most of the time.

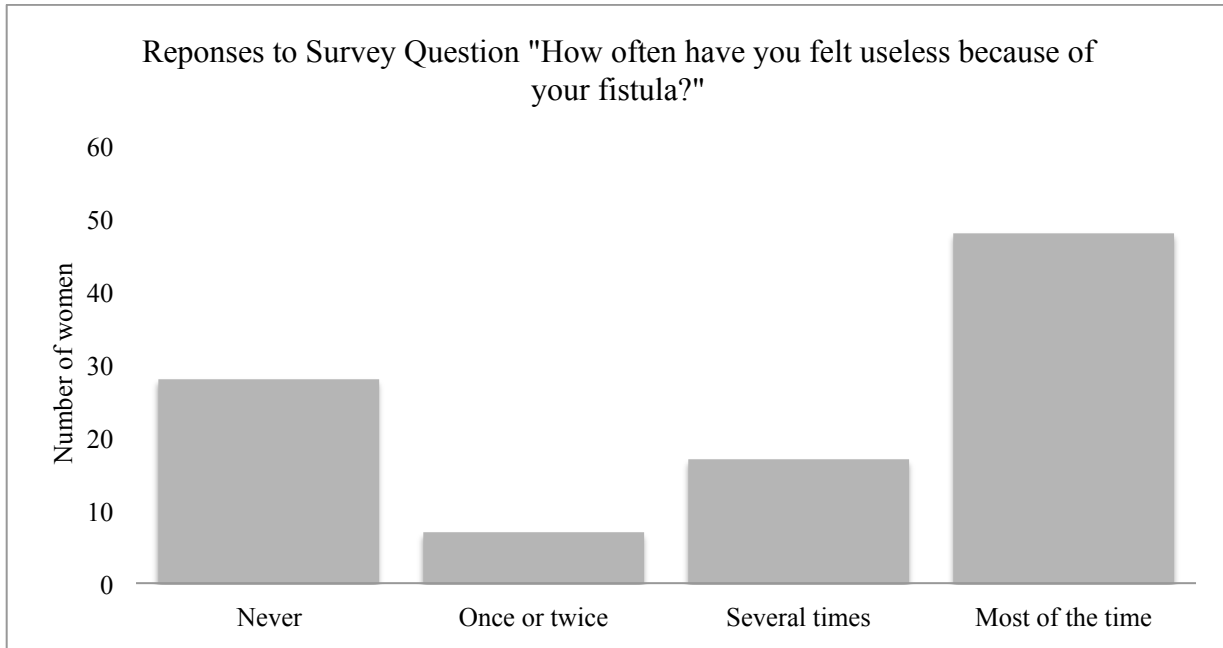


Figure 10.6: Responses of 100 women to stigma survey question asking, “How often have you felt useless because of your fistula.” 28 women responded “never,” 7 responded “once or twice,” 17 responded “several times,” and 48 women responded “most of the time.”

Binta, a twenty-six-year-old Hausa woman, was not able to work outside of the house due to the unremitting flow of urine and her constant foot pain caused by nerve damage sustained during labor. She worried that others would gossip about her, “people, they might say ‘She only eats and shits, what’s her use?’” Thirty-seven year old Zina worried that because of her fistula, her co-wives had come to resent her; she feared that they might say, “It is us who do all of her work for her because she is always sick’.”

Fifty-year-old Habsu, complained that she had lost weight and was “malnourished like a child” because she was dependent on others to bring her food. Although she had previously sold millet used to make *fura* (a milk-based drink), she had stopped, fearing that no one would buy from her because of her fistula, “To be a woman with value (*darijar*), you must make yourself useful. But with this sickness, I cannot work. So now I am poor and without use.” Twenty-six

year old Salamatou farmed before she contracted fistula, but stopped after she became ill. “I don’t do anything. I am in the house,” she complained. Her finances were affected, leaving her with no money to take care of her needs.

Mselle and colleagues’ (2011) framework for understanding the fistula experience focuses on the “deep sense of loss” the condition causes women, specifically identifying (1) the loss of body control, (2) loss of dignity and self-worth, (3) the loss of the social roles as woman and wife, and ultimately, (4) the loss of integration in social life. My ethnographic findings parallel this framework, with local correlates being the experiences of (1) shame, (2) ruined identity, and (3) uselessness. Among women with fistula in Niger, I found that the final loss in Mselle’s framework (the loss of integration in social life) often came as a consequence of women’s attempt to mitigate, manage, or reduce the intersecting losses experienced by shame, ruined identity, and uselessness.

10.5 Power, Structural Violence, Multiple Burdens of Poverty and Fistula-Stigma

The classic understanding of stigma—as an indelible and inexorable outcome of certain illnesses that render bodies as socially aberrant and morally degenerate, fails to recognize what Link and Phelan (2001), Castro and Farmer (2005), and Parker and Aggleton (2003), and many anthropologists and theoreticians now recognize: it takes power to stigmatize (and, complimentarily, the lack of power to be stigmatized).

Stigma must be viewed within larger economic and political processes, as grounded in social inequity, control, and power—a consequence of structural violence. Link and Phelan’s (2001) stigma work represents a critical step towards viewing stigma as a process influenced by structural power: “access to social, economic, and political power allows the identification of difference, construction of stereotypes, the separation of labeled persons into distinct groups, and

the full execution of disapproval, rejection, exclusion, and discrimination” (2001:367). They assert that without power, labeling and stereotyping do not transform into the nefarious process of stigmatization, “what matters is whose cognitions prevail—whose cognitions carry sufficient clout in social, cultural, economy, and political spheres to lead to important consequences for the group that has been labeled as different” (378).

Castro and Farmer (2005) build from Link and Phelan’s (2001) conception of stigma, proposing structural violence (manifested in racism, sexism, political violence and poverty) to be at the heart of processes of stigma, while Parker and Aggleton (2003) argue position stigma as a powerful tool to produce and reinforce relations of power and control and may be employed to understand social inequality and exclusion. Parker and Aggleton argue that stigma must be understood within a larger context of power and domination as it works with structures that create mechanisms of exclusion and strengthen and reproduce social inequities of class, race, gender, and sexuality. They argue that previous work on stigma has largely been limited by the focus on perceptions, beliefs, and attitudes of those who are perceived to stigmatize others rather than social conditions that result in exclusion. Additionally, Parker and Aggleton encourage stigma and discrimination to be understood within a context of the “political economy of social exclusion,” examining how economic restructuring and global transformations have “almost everywhere reinforced pre-existing inequalities and exclusions, such as racism, ethnic discrimination, and religious conflict” (2003:19). Thus, they shift the conversation of stigma away from individual psychology and towards sociological and anthropological discussions of the intersection between culture, power, and difference.

The importance of integrating contexts of political and social power inequities into constructs of stigma is particularly salient when examining fistula-related stigma, as fistula

already targets populations with compromised social power, namely rural women who are often resource poor, under-educated, and whose agency is frequently constrained by limited options and access. Parker and Aggleton's (2003) and Castro and Farmer's (2005) analysis of power, domination, and control, suggests answers to the question of why fistula is stigmatized when other conditions are not. Stigma surrounding obstetric fistula may be interpreted as a way of upholding the status quo and reinforcing gender norms within pro-natalist societies, where the inability to transition into womanhood via motherhood is punished through the loss of social status.

However, the analysis of power's influence on the attribution of fistula-stigma cannot end there. Assuming that all women in Niger (or in the Global South generally) experience similar degrees of powerlessness is problematic. Not only does an analysis of power aid in understanding why fistula is singled out among various conditions, but also it aids in understanding why some women with fistula experience intense social stigma while other women do not. In line with Parker and Aggleton (2003) and Yang et al. (2007), I argue that fistula-stigma is a frequently negotiated, and often resisted process whose severity is chiefly dependent on existing social relationships, working to reinforce pre-existing dynamics of power imbalances. Indeed, I found that young women, women without mothers or individuals living outside of the protective boundaries of familial advocates, and women who were otherwise already engaged in unequal power relationships were the most vulnerable to social exclusion and discrimination. Conversely, women whose social status was less precariously moored in local relationships of power (such as women with strong familial advocates, older women, or women with living children) were largely able to resist external (and often also internal) fistula-stigma. Rather than causing negative social consequences (often uncritically framed as 'stigma'),

obstetric fistula is often only an exacerbating factor of already precarious social contexts and unequal power relationships. The varying vulnerability to fistula-stigma elucidates social inequalities and gender dynamics in Niger.

I interviewed Fati, a forty-two-year-old Tuareg woman from Mali, three times, once at the fistula center and twice at her father's home in Niamey in the months following her return home. Fati had lived with fistula for eleven years before seeking treatment, and although she was healed after her first surgery, she began to leak again not long after her three-year-old daughter was born. Fati lived in a shed-like structure in the corner of a large lot where the carcasses of ravaged semi-trucks were sent to rust away. Her father was employed as the guard, but he had recently fallen ill (and incidentally also suffered from incontinence due to his illness). Fati spent her days worrying about where they would go if her father lost his job and how to make ends-meet and fill her daughter's belly as his wages declined during his illness. Her house had walls made from a handful of wooden beams and interwoven bags that once held cement and rice. The ground was sand. The roof a single sheet of corrugated tin with plastic bags balled up and stuck into the holes where the tin had rusted through. She lived with her father, her stepmother, and their children. About ten of them called the shack home. Although there was tension between her and her stepmother, particularly since her father had been ill and money had gotten tighter than usual, she explained that here she could eat at least one meal a day. "When your parents are separated, it is hard to find a place for yourself to be. In Mali, I would go two days without eating anything. And then, I might only eat the chaff of millet. Here, there is enough food for my daughter. We eat once or twice a day. So I stay here and make do."

Fati's life had been a difficult one, enduring the multiple burdens of poverty, ethnic discrimination, illness, and a health care system crippled by the recent political instability in

northern Mali. She explained that her fistula was not the determining factor in her life-narrative of mistreatment:

Even before I had fistula, people mocked me. I was very poor, and for people who are very poor, even if you don't do anything, even if you aren't sick, people mock you. But if you are rich, people want to be close to you. A rich woman can get a fistula, but as soon as she's at the hospital, she'd be seen; she'd be fixed. If a woman is rich and she gets fistula, people won't run away from her. They wouldn't dare mock her. They'd come to her as soon as she called. No, they wouldn't mistreat her. They would say, "God has his reasons." But when a poor woman gets fistula, they will mock her and say that she got fistula because she is poor or because she has behaved badly. With poverty, if you fall ill, and you have no money, it is so hard to get better. Getting medicine, getting enough to eat—sometimes it is impossible. You sometimes have a hard time getting one meal a day, and almost never more than that. So, if someone by the kindness of God gives you 500cfa [approximately USD \$1], you can buy some gari [dried manioc flour] and eat. But that's all. And if you are sick, you can't get better like that.

Later in the interview, I asked Fati if it was it hard to be a woman in Niger. She explained, "Being a woman or a man, it doesn't matter if you are poor—being poor is hard on both. But, poverty brings more helplessness to a woman than to a man. If you are rich, then as a woman you can be a man's equal." Fati shook her head and looked me in the eye, fingering a single coin she had been holding on to, "Before I got this sickness I was a poor woman. But when the sickness came, I became poorer."

For Fati, fistula exposed, and potentially exacerbated, but did not create, already existing power differentials and intersecting burdens of poverty. In line with Fati's perception of fistula stigma and poverty, Mselle et al. (2011) note how existing issues in inequity help define the experience of fistula: "The vast majority of women affected by obstetric fistula in this study constituted a socially weak group even before their birth injury...As documented in this work, the women's physical and social disability due to the injury pushes them further into marginalization, making them vulnerable to social exclusion and discrimination."

Indeed, Fati believed that the experience of fistula was entirely contingent on pre-existing social status and power. As a poor woman, she saw fistula as exacerbating the mistreatment she endured from community members due to her lack of means. She hypothesized that if a rich woman was to develop fistula, her community would embrace her and offer her support, and that her wealth would facilitate a speedy recovery from the illness. Fati saw poverty as a barrier to care and recovery, indicating that without financial means women had difficulties securing surgeries and that without proper nutrition women's bodies were unable to regain strength.

Because increased poverty is often linked with rurality, and because both of which are independently linked to barriers accessing health care, fistula is far more prevalent among poor and rural women.

* * *

An integral component of the popular representation of fistula is the profound stigma thought to surround the illness. However, while fistula is said to be a source of intense social stigma, there has been little discussion of what fistula-related stigma means, how it changes over the course of a woman's life, or who is vulnerable to it and why (and conversely, who is able to avoid it and why)? Instead, fistula-stigma is reified, simplified through a Goffman-esque lens as a trait which invariably spoils social identity. The critiques of classical stigma concepts emanating from both sociology and anthropology facilitate a more nuanced investigation of fistula-stigma, one which is sensitive to dynamic social contexts within which fistula-stigma may be created and perpetuated.

When I began the project, I expected to find heavily stigmatized and largely abandoned young women who were finding corporeal and social redemption only through the surgical removal of their stigmatizing attributes. However, despite the analogies that circulated in the

media and academic literature between leprosy and fistula, as I became more immersed in women's stories, I discovered a vast diversity in women's experiences of fistula-stigma and the degree to which it depended on a woman's larger social context—the quantity and quality of her social ties *before* she developed a fistula and pre-existing power dynamics. I found that external stigma was rare, with only the women who were already situated in the most precarious of social situations experiencing significant mistreatment due to their conditions. These women were likely to be living without the protection of a mother and staying for significantly longer periods of time at fistula centers than their counterparts. Conversely, I found that internal fistula-stigma was pervasive and was marked by shame, identity loss, and feelings of valuelessness and uselessness.

Arguably too much focus has centered around the behaviors of “stigmatizers”—hardened family members, callous husbands, and uncompassionate members of a woman's community—overlooking the more interesting question of fistula- stigma: why are some women able to resist “spoiled identities” while other women are not? Focusing on the perceptions of stigmatizers leads to interventions which aim to disabuse misinformed individuals of “incorrect” assumptions about fistula (that it comes from “bad spirits” or morally corrupt behaviors of women such as infidelity, for example), rather than aiming to address the systemic factors which makes some women vulnerable to compromised negotiation power and enhanced vulnerability within their social networks. Understanding stigma instead within a political economy of social exclusion, or the context of power and domination reinforced by historical trends and political processes which have exacerbated (and sometime created) inequities of class, race, and gender, may illuminate why some (but not all) women are made vulnerable to the social consequences of obstetric injuries. Beyond obfuscating systemic inequalities, this assumption can even prove

detrimental for women with fistula. In an attempt to correct flawed community perceptions (perceptions which are thought to generate stigma), clinics may unintentionally “out” women who have successfully concealed their incontinence.

Rather than an inevitable consequence of fistula, the narratives of women like Hasana, (the twenty-year-old motherless woman who recounted neglect and mistreatment from her father and stepmother), who experienced the worst external stigma, reveal how fistula exacerbated tensions in already fractured social networks. Fistula-stigma grew from—but did not create—structural disempowerment.

Following the traumatic labor that caused fistula, Hasana was sent directly to a fistula center, never returning to her natal (or her marital) home until her fistula was successfully healed. Not one person in Hasana’s social network saw or smelled visible evidence of her wetness. That Hasana (who no longer was physically ‘marked’ by fistula) endured more external social stigma than 94% of women in the sample (and more internal stigma than 91% of women in the sample) demonstrates an integral aspect in understanding fistula-stigma, its dependence on existing social contexts and the internecine way in which it synergizes with extant power disparities. Hasana’s inability to overcome fistula-stigma, despite her lack of fistula, highlights the importance of understanding possibilities for destigmatization, as well as resistance, (re)negotiation, and reproduction of fistula-stigma, which will be considered in the following chapter.

Chapter 11

After the Stitches: Conceptualizing Destigmatization of Fistula-Stigma

While social stigmas have been extensively theorized, resulting in various conceptual models of stigmatization processes, there is a paucity of theoretical investigations of destigmatization, or ways in which stigma may be reduced, modified, or erased (*see* Coulter and Maida 2005; Haghigat 2001; Spencer 2006; Trice and Roman 1975; Warren 1980). According to Warren (1980), “Stigmatization is a more common process in our society than destigmatization... The empirical situation is paralleled by the theoretical situation... there is no systematic theory of destigmatization” (59). Even in literature explicitly about “destigmatization,” the concept is not looked at theoretically, but rather as an implicit result of the erasure of stigmatizing characteristics (Coulter and Maida 2005; Navon 1996; Spencer 2006). While it is widely recognized that stigmatizing attitudes are resistant to change (Hinshaw 2007), there is evidence that sometimes these attitudes *do* change, sometimes groups and individuals are able to shed stigmatized identities (Spencer 2006). However, investigations of destigmatization focus almost exclusively on policy critiques or recommendations regarding interventions intended to reduce stigma, resulting in an elision of theoretical considerations. Indeed, if stigma may be interpreted as strategically deployed by social actors seeking dominance within structures of inequality and ultimately reproducing social distinctions (see Bourdieu 1984 on symbolic violence; Link and Phelan 2001; Parker and Aggleton 2003), theoretical formulations of destigmatization must engage with the question why would those in power allow for

destigmatization to occur at all? Building from the previous chapter's reconceptualization of fistula-stigmatization as a process, applied unevenly to women and highly dependent on pre-existing factors of power, status, and social vulnerability, destigmatization of fistula-stigma must, in turn, be understood as highly dependent on embedded social dynamics.

In this chapter I explore what happens after the stitches, when successfully operated, post-surgical women with fistula are no longer marked by physical difference. I observe transformations in healed women's social interactions in order to examine processes of destigmatization of fistula-stigma. While I began this project looking to uncover if repaired bodies lead to repaired selves and ultimately to repaired social relationships, I found that if, how, and to what extent women experience destigmatization of fistula-stigma has very little to do with the transformation of women's physical bodies. Ultimately, I argue that processes of destigmatization of fistula-stigma are highly dependent on women's pre-existing social contexts and power disparities, resulting in thorough and unproblematic destigmatization for some women and unmitigated fistula-stigmatization for other women. I also explore women with fistula's strategies for fistula-stigma resistance and refusal, and even fistula-stigma reproduction.

11.1 Theorizing Destigmatization

Public Health Approach to Destigmatization

While social stigmas have been extensively theorized, resulting in various conceptual models of stigmatization processes, there is a paucity of theoretical investigations of ways in which stigma may be reduced, modified, or erased (Trice and Roman 1975; Warren 1980; Haghigat 2001; Coulter and Maida 2005; Spencer 2006). Destigmatization research is tackled most frequently in the domain of public health or development, endorsing what Gussow and Tracy (1970) refer to as the "destigmatization theory," the belief that stigma is the result of

“myths or misconceptions,” and thus the dissemination of “correct” information alone will change community attitudes, promote social integration, and ultimately reduce or remove social stigma (Krishnatray and Melkote 1998; Weiss 2008). According to Gussow and Tracy’s investigation of leprosy-stigma:

The destigmatization theory rests its case on the assumption that stigma is nearly ubiquitous and informs us that as the misconceptions with which leprosy is surrounded are corrected, social ostracism and rejection will appreciably diminish and perhaps even totally disappear... A rational view of leprosy, based on the known facts of the disease, will reverse or slow down the stigmatization process. (1970:426, 429)

Indeed, for many leprosy treatment and eradication initiatives, interventions focus on developing community knowledge of leprosy as treatable and creating “a reasoned and rational attitude towards patients,” with the hope that this will promote social integration (Melkote et al. 2008:132). These programs continue to operate premised on the belief that “local people lack a logical understanding of the concepts, cause, and cure of leprosy, and that the diffusion of ‘expert’ knowledge will overcome low awareness and effectively destigmatize leprosy” (132). This perspective is endorsed not only by on-the-ground policy makers, but by many scholars (see for example Martin et al. 2000; Morrison 1980). According to Read et al. (2006), “A core assumption of many anti-stigma programmes has been that the public should be taught to recognize the problems in question as disorders, illnesses, or diseases, and to believe that they are caused primarily or exclusively by biological factors like chemical imbalance, brain disease and genetic heredity” (304). Indeed, such a perspective is still widely adopted, as evidenced by this recent commentary on mental health-stigma: “If the causes of mental disorders were attributed to factors outside the individual’s control, people’s reactions to those with mental illness would be less negative” (Angermeyer and Matschinger 2005).

Although this understanding of destigmatization is widely accepted, it is frequently proven untrue. In researching mental health related stigma, Pescosolido and colleagues (2008) found that previous understandings of stigma, which attributed the process of stigmatization leading to “spoiled social identities” largely to mis-(or lack of) information, were unable to account for complex and recalcitrant processes of (de)stigmatization. “Stigma was expected to abate with increased knowledge of mental illness, but just the opposite occurred: stigma in some ways intensified over the past 40 years even though understanding improved” (Pescosolido et al. 2008:433).

Reinsertion or reintegration efforts integrated into fistula campaigns are largely influenced by public health approaches to destigmatization. According to educational material produced by the organization Every Mother Counts, “Communities need to understand the true causes of fistula so that stigma within society can be reduced” (everymothercounts.org). They add, “A social information and awareness campaign is also needed to reduce stigma and to inform women living with fistula and their communities that they are not alone or ‘cursed’ and that treatment is available” (Ibid.). This approach to fistula awareness raising (with the expressed intention of reducing fistula-stigma) is extremely common. In the most neutral of consequences, this type of approach is simply ineffective as it overlooks the structural and social dimensions of stigma, specifically that fistula-stigma results not from ‘myths or misconceptions’ about the illness or its etiology, rather from the social context in which a particular woman is embedded. However, there are more harmful consequences as well. As discussed in chapter six, based on the belief that an increased awareness about fistula will decrease stigma, many centers accompany women who have been healed back to their villages. In an effort to disabuse community members of flawed beliefs surrounding fistula (which is assumed to be the cause of

stigma and mistreatment), center staff frequently “out” women, exposing the recently healed woman (who may have successfully concealed her condition) as someone with fistula. Even if the woman had not been concealing her condition, this approach is at the very least probably ineffective in reducing stigma as it fails to address (or even recognize) the complex social factors that may support the development of fistula-stigma.

Stigma as Sticky: No Fistula, but Enduring Fistula-Stigma

Some anthropological work suggests that despite treatment, increased knowledge, and social awareness that a condition is treatable, stigma is “chronic” or “sticky, enduring, and difficult to shed” (Best 2003:61; Barrett 2005; Prescosolido et al. 2008). Recent work on post-surgical bodies also affirms the difficulty of individuals to free themselves of stigmatizing ‘sick roles’ in the public imagination (Crouch and McKenzie 2000; Manderson 2011; Maynard 2006). Additionally, Freidson (1970) and Scambler (1989) argue that even when a stigmatizing attribute has been erased, an individual’s identity will still be “spoiled.”

Of particular interest when examining destigmatization processes of fistula-stigma is the body of literature on stigma related to treatable illnesses or conditions. Some scholarship has focused on the lived experiences of individuals who undergo surgical procedures in order to “fix” flawed bodies. Lenore Manderson (1999) explores the links between corporeality, identity and sexuality among individuals who have undergone major life-saving surgery resulting in amputations, reconstructive surgeries, stoma bags, or mastectomies. She explores the process of “normalization” after surgery to “accommodate physical changes and to allow their (sense of) social reintegration” (382). For many individuals, while surgery “fixed” their bodies, their sense of self remained broken: “[surgery] has killed my confidence. *Normally* I’m overconfident. Whereas now I’m quite embarrassed about my body, even though therapy brought me back to

normality” (emphasis in the original. Manderson 1999:388, quoting an informant). Indeed, contrasting destigmatization literature which assumes that the erasure of stigmatizing attributes through surgery equates with restored un-stigmatized identities, Manderson suggests that the reality is more complicated as individuals struggle (and frequently fail) to “re-establish normalcy” (392).

Some recent research in stigma related to illness has asked the question: does stigma persist after treatment? Jenkins and Carpenter-Song (2008) argue that despite being medically treated for psychosis, and experiencing relative recovery, stigma persists. In their article “Stigma Despite Recovery,” they claim that of their participants, 96% reported perceptions of stigma across a variety of social settings including work, family, friends, and their romantic lives (Jenkins and Carpenter-Song 2008:386). They assert that for the individuals studied, “their subjectivity is saturated by intense awareness of social stigma that seems intractable in relation to temporal or functional criteria” (2008:381).

Similarly, in a study of patients with Hansen’s disease in northern India, Barrett (2005) suggests that despite treatment, and the social awareness that the condition is treatable, stigma persists. This is demonstrated by a quote from one of his informants treated for leprosy: “The burden is worse than the bacteria. You see, the infection is easily treated, easily cured with [multidrug therapy]. . . . But even when the leprosy has been totally eliminated, many people will treat you as someone who is cursed for all time. That is the major problem” (Barrett 2005:216). Indeed, Barrett asserts that in all of his case studies, while a few individuals were able to mitigate “their untouchability” in public urban spaces, none was capable of reuniting with their original households (2005:218). Barrett suggests that because individuals treated for Hansen’s disease in northern India are “marked for life,” they frequently embrace (and even exacerbate) physical

deformities that enhance the success of begging and thus serve as their primary means of survival (2005:224).

11.2 After the Stitches: Fistula and Destigmatization

To understand women's experiences with destigmatization of fistula-stigma, I interviewed twenty-one women who had previously been healed of fistula, of whom two were healed during the research period (and were re-interviewed following their cure), nine were healed of fistula before the interview (but returned to centers because of other health complaints, prophylactic C-Sections, center trainings, or to collect money), and ten others were wet at the time of interview but had been previously healed of a fistula (all of these women had recidivistic fistula). Unsurprisingly, the women had a variety of experiences, as some were able to continue with their lives, socially unmarked by their period of illness, while others felt indelibly marked.

“Once a *fistuleuse*, always a *fistuleuse*”

Hasana, a twenty-year-old Mossi woman with fistula whose mother died while birthing her, was one of the seven women who experienced the worst external fistula-stigma from the previous chapter. Although Hasana was dry, and had, in fact, never lived with her family while incontinent, she experienced a near-constant external fistula-stigma from her immediate kin, who continued to treat her as a woman with a “broken vagina” despite her cured body: “With [my family], as soon as I get up, they look to see if my wrapper is wet.” Hasana recounted experiences of insults, mistreatment, and avoidance behaviors of others, reinforcing notions of external fistula-stigma tied to the condition. According to Hasana, the mistreatment she endured at home was not because she smelled or leaked, for she did neither once she returned home to her family.

Rather, Hasana attributed her mistreatment to her social vulnerability due to the fact that she had no mother, “Without the protection of a mother, no one would protect me.” I asked Hasana if her father tried to protect her from mistreatment; she angrily responded, “No, it is not his concern (*ba ruwanshi*). He does not care. He will not even buy me anything—not even soap. When I got fistula, he did not even come to the hospital to see me. Not once. I do not know what I did so that he rejects me like this.” When I probed into the nature of her relationship to her stepmother, she confessed that her stepmother would insult her and would even deny her food: “My family will not eat with me, even now that I am dry. I have to rely on the generosity of friends and eat with them, otherwise I would starve.”

Although fistula no longer marked Hasana’s physical body, it continued to mark her social body, constraining her social networks and inhibiting her chances of remarrying:

Since I am healed, a few men have proposed to me. But, when the time for marriage comes, people tell the man that ‘she had fistula before and she could get it again’. They convince him not to marry me; they tell him to leave me. So, the men don’t marry me... This happened last year with another man. So, I came here [to the fistula center].

In an attempt to distance herself from an abusive home and unabated social injury, which I believe had less to do with her fistula than the precarious position she occupied in her home, Hasana sought refuge at a Niamey fistula center. She was termed by the staff as an “Ambassador of fistula,” meaning that although Hasana was no longer wet, she chose to leave her family and her village and move to the center, helping with the daily maintenance of the center, and offering her personal testimony when the center needed a “face of fistula” for publicity.

Rather than benefiting from the “sisterhood of suffering” at the fistula centers, however, Hasana was often insulted by women with fistula at the center who did not understand why a healed woman would opt to remain away from her home. Thus, insults came from every direction, “People mock me all of the time at home. Now, I have even seen it with my own

eyes... If it didn't hurt me so much, I wouldn't be in Niamey. But even here [at the fistula center], women [with fistula] gossip about me. They say 'if she is healed, why is she here?'"

Hasana explained, "Even now that I am dry, people run away from me all of the time." The year before I met Hasana, she had been paid by the center to tour several villages, speaking about fistula in the hopes of raising awareness of the condition in hopes of reducing fistula-stigma (following the center's public health approach to destigmatization). Hasana recounted:

After speaking, I asked a woman who had listened to me talk for a glass of water. Her child brought water for me. After I drank it, I heard the woman tell her daughter in Fulani [language]—which the woman thought I did not speak because I do not look Fulani—not to put the cup back with the other cups, but to wash it first—as though I were contagious. I live with that sort of unkindness.

Hasana's experience with this woman and her child highlights the flaws of destigmatization theories which depend on "awareness building" to diminish stigma.

Some people in the village say "it's because your mother is not alive that your father and step-mother treat you like this"... Even though I am healed, some people still don't accept me. Even today if I go back home, if I sit down and then I stand up, people will watch me to see if there is urine or not. Really, it's why I don't want to go back home in the village. It's an obligation to go home, but I don't really want to go back there.

That Hasana experienced such acute and unmitigated external fistula-stigma *after* she was healed of fistula (and, indeed, she never lived at her nuptial or natal home with fistula) is powerful evidence that fistula-stigma, and in turn, fistula-destigmatization, does not solely depend on the transformation of the external "mark." Hasana's story reveals the way in which women's ability to overcome fistula-stigma depends on the same factors as their ability to prevent fistula-stigma in the first place: power and status within their communities.

Similarly, Hassia, a twenty-seven-year-old Zarma woman who had been healed of fistula for three years, explained that despite cure, her life continued to be impacted by fistula. After she was healed, her family decided it was time for her to restart her life and remarry. Although

Hassia's first husband (who divorced her following her prolonged absence from home while she sought care) was her age-mate, her family chose a second husband for her who was older than her own father, explaining to Hassia that they did not believe that a young man would treat her well. Her family feared that because of her fistula, her fertility would be compromised. They reasoned that a young man would mistreat her if she were not able to have children because of her fistula, while an older man who already had children might not. She was married against her will to the older man, and fled to a fistula center in Niamey to avoid consummating the marriage. She had been at the center for two years when I met her. She explained to me that despite being healed, the identity of a woman with fistula was indelible:

If you are sick and you are healed, your life won't be like it was before. What you could do before has changed. You can't do those things anymore... They won't forget [about your fistula]. People think that if you were once a *fistuleuse* [woman with fistula], you are always a *fistuleuse*. Even if you are healed, that changes nothing.

Saouda, a thirty-year-old Zarma woman who I interviewed several times, both before and after she was healed of fistula, frequently returned to the center even after she attained continence. Saouda's home life was difficult and full of rejection, "Often the people in my house would say that I did it on purpose—that I peed on purpose. They'd cover their noses when I was near.... People in my house were the only ones who did this—people outside of the house would even advise my family to take care of me."

Following her first surgery, Saouda attained continence. She returned home, but three months after her surgery, she returned to the center looking much thinner than she had been a few months before, and with a greyish pallor and large splotches on her head where she had lost her hair. Saouda admitted that when she returned home healed, her family continued to mock her, saying, "You there, you've sold everything that you own. Now you have nothing!" Before she was healed, she remembered how her family had frequently told her that she was responsible

for her fistula, “They said that I got fistula because I sinned.” Despite her physical transformation when she was healed of fistula, these insults persisted, “But now when they say it, I don’t listen.”

Saouda admitted that life back home had not changed much as few people believed that she was healed, “People in the village, they say that I am lying; they think that I am not healed. They still stare at my wrapper... Even though I am healed, people say that I lie and that I will stay forever with the fistula.” Indeed, it appears that women with the most extreme experiences of external fistula-stigma, often due to external factors of social vulnerability, are unlikely to experience destigmatization of fistula-stigma despite cure. Rather, family members and social contacts appear skeptical of cure, and often continue with mistreatment and isolating behaviors towards women.

“No one runs from them, no one insults them, they are with the people”

Conversely, many women who were healed felt that their lives had returned to how they were before fistula. Kadi, a thirty-three-year-old Zarma woman who developed a fistula following her seventh pregnancy, was a reserved woman who seldom smiled. She identified as an introvert, “Unless I am close to someone, it isn’t my nature to spend lots of time with people.” Kadi lived with her husband and five children in a village approximately one hundred kilometers southeast of Niamey. Partially because Kadi had managed to conceal her fistula from most of her community, partly because she did not have a thriving social life before she fell ill, and partly because Kadi commanded some respect in her community —married to a well-respected son of the village chief, she had not experienced much mistreatment due to her fistula until she arrived at the fistula center.

Kadi explained to me that although fistula did not exist in the time of her grandmothers, recently four women in her village had developed the injury. Still, she averred that “In my village, no one mistreats women with fistula—no one runs from them, no one insults them, they are with the people.” In fact, it was only at the center that Kadi experienced any mistreatment because of her fistula, witnessing other patients and visitors at the hospital covering their noses or spitting when they passed the area where the women with fistula were housed.

Five months after I initially interviewed Kadi, she had undergone surgery and returned home continent. My research assistant and I visited her in her village two months after her return. Nestled in a small valley many miles from the dirt road, Kadi’s house was small, with only two rooms. The walls were made of mud and the floor was uncovered dirt. We sat on a mat in the barren room. Her small children played around us, filling the hot air with dust, rendering each breath a challenge. Dust coated my throat and teeth and filled my lungs. Kadi explained that since her return, she had no problems:

Before I went to the hospital, people would come to visit, but stop at the door. They’d say that the room smelled bad, that it smelled like urine because of my sickness... My oldest son, when his friends came they would look at my feet to see if there was urine. But now when they come, they don’t try to see if there is urine. Now people come to visit with me, but not because they are curious as they were before.

Kadi explained that she had overheard people talk about how her and how she was now healed:

One day I went to the river to wash. There were two women and I heard one say, “Look, [Kadi] suffered so much this year.” The other said, “Yes—now she has even gained weight! She doesn’t have the sickness anymore”... Now when I go out, people ask if I am the same woman. I’ve gained weight. I’ve changed. People talk so much about it, I am afraid that it will attract the evil eye.¹⁰² Before [with fistula], I didn’t even want people to talk to me—I was annoyed and bothered by the company of others. I didn’t want to be with people. Now, I chat with people freely. I don’t even want people to leave when they come to visit!

¹⁰² In Niger, overt compliments are often avoided because they are thought to attract the attention of the “evil eye” or bad spirits. In order to avoid such attention, compliments are avoided, particularly about young children and babies who are thought to be particularly vulnerable to the attention of bad spirits.

When she was ill, Kadi had stopped attending religious courses (*makaranta*) and attending other community events, but since her return home, she had begun again. Still, Kadi continued to struggle with some lasting consequences of fistula, particularly the limits her extended period of recuperation placed on the type of labor she was capable of undertaking, limiting her ability to fully reassume her responsibilities in her household and in the fields, and the tension prolonged abstinence placed on her marriage. Yet, these struggles fit within the larger context of her life and relationships, rather than representing a clear break due to fistula. Largely, Kadi was able to resume the life and social relationships that she had before her fistula.

“If someone rejected you, you will keep it in your heart until the day you die”

Other women noted that despite cure, and despite an outward appearance of a reestablished normalcy, their emotional lives continued to be affected by their experiences with fistula. Many women explained that although their quotidian lives were able to return to “normal” after they were healed of fistula, their internal lives remained forever changed by the experience of illness—marked by betrayal and hidden anger. Many women recounted selected incidents of mistreatment and spoke of their inability to excuse or forgive individuals who wronged them when they were unwell. For example, Nafisa, a thirty-year-old Zarma woman, spoke of a woman in her village who had developed—and then subsequently was healed of—fistula:

She was a niece of my husband. When she had the sickness, her brothers even hit her; they told her that she shouldn't stay in the room with them—that she smelled bad. If she brought a plate [of food], as soon as she put her hand in, they wouldn't eat the food. If she went to the bathroom, the urine would run everywhere, all over her feet. She'd spend her days crying. Her mom said that she'd maybe never get better. I really pitied her.

However, after one surgery, the woman regained continence. Nafisa noted that despite her poor treatment at home, once she was healed, her life returned to how it had been before her

fistula: “When she was sick, people pushed her aside. But now that she is better, she can do anything.” I asked Nafisa if this woman was able to reestablish the relationships that were broken when she was ill. Nafisa shook her head and explained that betrayals so grave could never be forgotten:

You can't forget it if you are mistreated. If someone took care of you, if they washed your wrappers and brought you food, as soon as you have something, you will give it to them. But if someone rejected you, if someone mistreated you, you can't forget that. You will keep it with you in your heart until the day you die.

Reflecting upon her own case, Nafisa explained that she would forever remember the mistreatment that she endured:

For me, there are people like this—people who mistreated me. Even my sisters. My younger sister refused to wash my wrapper. An older sister found my wrapper soaked in urine and insulted me, asking why I would wet myself, saying that my room smelled bad. Once when she went to the clinic with me, she sent a child to buy perfume to pour on me because she said I smelled... Even if I am healed, even if I act as though things are like how they were before, I will always remember how they acted.

Similarly, Hajera, a fifty-year-old Songhai woman who experienced mistreatment due to her fistula, explained that even if she were healed, she could never forgive her friends and family who wronged her, “I will never forgive them. My heart will not tolerate that. I will stay with them; I will sit with them. But to forgive them... I don't know. I don't think so.”

Because it is not fistula itself that is ‘stigmatized’ (as no one can see fistula), rather fistula becomes one more factor that exacerbates power differentials (like gender, lack of power within the household, lack of advocacy, ethnic tensions, and poverty), women who are healed are not de facto destigmatized. However, following the closure of a fistula, its sensorial symptoms that can be used to mistreat or insult women (such as smell, visible wetness, constrained sexuality, etc.) are no longer relevant. The absence of these factors often results in the drastic reduction of both external and internal fistula-stigma, experienced as a significant reduction of outwards

mistreatment and individual shame and self-regulation through isolation. Still, for many women, although the visible symptoms of fistula abate, the social factors that facilitated fistula-stigma (such as poverty and social vulnerability) persist.

Additionally, the consequences of strict self-regulation do not disappear along with the closure of a fistula. As the search for care is often a long and tortuous journey, frequently causing prolonged absence from home, divorce, and spatial dislocation, women who are healed are often left with weakened social networks caused by extended periods of self-isolation or physical absence in the search for care. Although a woman's fistula may be healed, her social network may be even more difficult to repair.

I argue that destigmatization following fistula repair is (1) processual, (2) negotiated (or negotiable), (3) non-linear, and (4) dependent on local community dynamics, embedded social contexts, and hierarchies of power. Extant destigmatization theories from both psychology and public health rely on models of stigma which are overly deterministic, ignore complex social relationships, and do not account for power relationships. Just as fistula-related stigma is deeply entrenched in existing social fabrics and power differentials, so is the possibility of destigmatization.

11.3 Acts of Resistance, Refusal, and Reproduction of Fistula-Stigma

Existing frameworks of stigma, particularly those that draw from classical Goffman-inspired formulations of stigma, have been criticized for not offering room for stigmatized individuals to resist and refuse stigma processes. Indeed, many scholars assert that stigmatized individuals do defy stigma through quotidian acts of resistance and refusal.¹⁰³ For example,

¹⁰³ For example, in an analysis of early research on AIDS, Schoepf examines how a resistance movement began to take shape against the existing frameworks that blamed the spread of AIDS on backwards cultural practices and sexual deviance. She asserts that individuals began resisting the moralizing discourse surrounding AIDS through a

Jenkins and Carpenter-Song (2008) argue that individuals with mental illness who feel stigmatized employ a variety of strategies to resist the impact of stigma, demonstrating that “persons with these illnesses [psychosis] are often not only exceedingly socially aware but also strategically skilled in response to social assaults on their personhood and survival” (381). They cite myriad strategies for self-protection and resistance to stigma employed by individuals recovering from mental illness, including: concealing diagnosis or medications, avoiding others, attempts to “pass” for normal, de-emphasizing illness, relativizing illness, educating others about illness, socializing with others with illness, confrontation and opposition, humor and joking, and reproduction of stigma (ibid. 387). Although mental illness (and the stigma attached) is unquestionably different from fistula-stigma, the strategies employed to resist these stigmas are similar.

“If you smell bad, people will talk and that’s expected”:

Among women with fistula, stigma at the centers was tied not to the condition itself, but rather a woman’s ability (or willingness) to manage her incontinence through vigilant self-care. Unlike many women at the center who felt liberated from the quotidian pressures of fistula management at home through a “sisterhood of suffering” at the center, women who struggled to meet the standards of fistula self-management upheld by women at the center often felt profound discomfort, social isolation, and external (and internal) fistula-stigma.

Habsu, a thirty-three-year-old Hausa woman with a severe fistula, admitted that she felt socially isolated and judged by other women at the center. After a three-hour interview, Habsu seemed reluctant to leave the small, hot room where we had conducted the interview. I asked her

“political-economic construction [that] was elaborated and spread along the *radio trottoir*, or ‘sidewalk radio’ that carries popular culture in Africa’s cities. AIDS came to stand for ‘Acquired Income Deficiency Syndrome,’ a disease brought on by poverty, unemployment, and the strategies that poor people commonly adopted for survival” (Schoepf 2001: 342).

for her contact phone number, which was written on a scrap of paper, tucked into a cement bag with her other belongings in another room. Looking down, Habsu apologized for the mess that she would make as she slowly stood up. Within seconds, as though a large pot of water had been overturned, urine crashed against the concrete floor and flooded in all directions.

Not all fistulas are identical; not all incontinence is the same. Even for the women at the center who all suffered some degree of leaking, Habsu's incontinence was notable and engendered poor treatment, gossip, and to some extent, disgust from the other women—markers of external fistula-stigma. Other than that afternoon, in the many months that followed, I never again saw Habsu sit—she preferred to stand, lean, or perch her elbows on the top of a chair, attempting to mitigate the fistula-stigma she experienced. When I asked Habsu about it one day, she admitted to me that she was very aware of how her leaking was perceived by other women at the center, and how they thought about and treated her:

Women here [at the center] mistreat each other. They tell each other that they smell bad. The other women here always tell me that I smell bad, they tell me to leave. When I first came here, I was very sick. I couldn't even walk. The other women thought I was crazy... Even women here, they will look at my wrapper to see if I am wet. They are unkind to me.

Habsu's inability to conform to local norms of hygiene and self-management tacitly agreed upon by the women at the center resulted in their reproduction of fistula-stigma. Indeed, women often spoke negatively of other women with fistula who they perceived as "unclean." Ramatou, 20, explained that, "Some women don't manage well because they are not clean (*ba su da tsabta*)." Salamatou, 47, explained that, "Women who weren't clean before the sickness don't manage it well." Talata, 56, said, "Every day I wash and I wash. So, for me, women who smell, women whose feet are always wet, women who don't keep themselves clean, well, they are dirty to start." Dije, 37, explained that, "If you are always clean, no one will say anything

about you. But, if you aren't clean, if you smell bad, people will talk and that's expected. Women with fistula must *always* be clean." Thus, women with fistula themselves often reproduced fistula-stigma when others failed to meet standards of cleanliness and concealment.

The Empowerment Model: Capitalizing on Fistula-Based Resources

Shih (2004) argues that despite the difficulties that accompany stigmatization, stigma does not always translate into "poor outcomes" (as predicted by Crocker and Major 1989). Rather, Shih argues that stigmatized individuals frequently flourish because they adopt an "empowerment" model rather than a "coping" model, thus transforming adversity from a "depleting process" into an "empowering process". Individuals capable of thriving despite stigmatization frequently employ other strategies including: compensation, strategic interpretations of the social environment, and identity switching.

Although I would not argue that women with fistula adopt an "empowerment" model, the strategies described by Shih are evident in clinics (rather than within women's communities) as women capitalize upon the resources available to them. Women, even those previously healed from fistula, continue to use clinics as sites for economic and social growth. Because of fistula, women become eligible for a host of goods (such as sewing machines, cell phones, cash, foodstuff, and other items intended for income-generating activities) and services (such as free healthcare for conditions often unrelated to fistula, trainings, and microcredit lending activities) that are otherwise unavailable to their peers back home. Additionally, women expand their social support systems not only through the relationships they cultivate with other women with fistula, but also by establishing relationships with center staff (who typically comprise an urban, highly educated, and middle-class sector of the population that would otherwise be largely inaccessible to these poor, rural women). Women with fistula use the center not only as a site for

acute and short-term physiological intervention, but often use the centers throughout their illnesses as recourse from difficulties at home (often undesired arranged marriages), as sites through which their lives can be transformed (by looking for potential husbands located in the city), as a way to build status back home (through the cultivation of urban habits and knowledge), and as a way to ease financial strain (through the participation in reinsertion programs).

Generative Stigma and The (Re)Negotiation of Fistula-Stigma

While there is an assumption that fistula-stigma is a somewhat fixed, culturally acknowledged phenomenon, very few individuals in Niger have heard of a condition developed during labor that can result in chronic incontinence, and understandings of the local illness category “sickness of urine” are uneven and dynamic. Eighty-six women of one hundred in my sample were not aware of such a condition before they developed it themselves. Several women even admitted that only *after* they developed fistula did they learn of another woman in their family, village, or a neighboring village who had fistula. Due to the ubiquity (and apparent success) of concealment efforts (which will be discussed in the following chapter), often members of a community may acknowledge that a woman has “some kind of sickness” without being aware that it is fistula. According to Mida, 37, “Had I not been a victim of this sickness, I would have never heard of it. It was after I became ill that an aunt came to tell me about [her fistula]. She told me that she had surgery, but it failed... No one knows I think. It is only if you are close to her that she might tell.”

As most women with fistula had never previously heard of the condition before they developed it themselves, they did not already have a pre-existing framework within which to place their experience. In each community, each time a woman develops fistula, a new set of

meanings is created, negotiated, and assigned to the illness. The women themselves, their families, and their communities come to understand fistula in a highly context-specific way, where the meanings they attach to fistula is largely dependent on already existing social facts related to the woman. This makes the assumption of a set notion of stigma resulting from fistula—particularly as some sort of pan-African (or further still, pan-Global South) category—problematic.

The link that is frequently made between fistula-stigma and the stigma associated with leprosy is faulty. Leprosy, which marks the body in highly visible ways, is difficult (if not impossible) to conceal. Leprosy is widely recognized in Niger (in Hausa the word *kurturta* means leprosy, while fistula has no name, called *ciwon yoyo fitsare*, which translates as sickness of leaking urine, or generally, incontinence). Fistula, which manifests as chronic incontinence, does not mark the body in distinctive ways as does leprosy, rather, incontinence is a widely recognized symptom of ageing, other illnesses, and even some venereal diseases. Rather than carrying a rigid stigma, fistula-stigmatization must be understood as a highly dynamic process, which varies for each woman and her community (as discussed in the previous chapter).

Frequently it is the fistula centers that meanings regarding fistula are created. During “sensibilizations,” or awareness raising activities conducted in the centers, in local clinics, and in communities, health trainers introduce fistula as a highly stigmatizing illness that engenders myriad social consequences. While the consequences of this approach are difficult to measure, I posit that this initial introduction to fistula may have long-lasting consequences whereby in the listener’s newly formed schema of fistula and stigma are inextricably linked. The chasm between women’s understandings of the illness from personal experience versus professional discourse became evident during interviews with women (where, for example, two women who

developed fistula during their seventh and twelfth pregnancies, respectively, explained that their fistulas were caused by “early” marriage, demonstrating the internalization of public health messaging regardless of how appropriate it is or is not for a particular woman’s life experience).

For individuals and communities without any previous contact with the condition, when a woman develops fistula in a village, the meanings surrounding the condition are highly variable and ever dynamic. Indeed, in these scenarios, the degree to which a woman with fistula experiences fistula-stigma is highly linked not only to the severity of the condition, but other social factors which mediate her power and position within her community and her household.

Hagera, an eighteen-year-old Zarma woman with fistula, explained to me that during the past year when she lived at home with fistula, she was able to manage it and conceal the condition from most other people. She explained that it was not until she arrived at the center that she understood that women with fistula were stigmatized:

I didn’t know that women with fistula were treated badly until I arrived here . . . The women I met here told me, and I learned from [the clinic staff] during trainings that women with fistula were mistreated and rejected. I learned that people run from them. Hearing this made it harder to live with this condition.

Due to her ability to conceal her fistula at home and the impossibility of “passing” at the fistula center, it was not until she arrived at the center that Hagera’s identity became so singly associated with her leaking body:

I feel shame because I have come to a place where all of the women here have fistula. I didn’t feel this shame at home. At home, no one knows that I leak, but here, everyone knows. People like you, [foreigners/visitors/voyeurs?] come to this center, they look around and say: [*mimicking her best impression of the French word ‘fistuleuse’*] “The women here are FISTILEESAY!” When I hear this word, I feel so much shame.

Although in English (or in Hausa or Zarma) there is no clear translation for the French word *fistuleuse*, *fistuleuse* is to fistula as leper is to leprosy. When she hears the word *fistuleuse*, Hagera becomes this word, and it is in that transformation—when she shifts from being a woman

with a birth injury, to a woman singly defined by fistula, that she feels shame. For Hagera, the center was not an oasis of judgment free relationships and acceptance, offering a “sisterhood of suffering” as so many have argued, but the opposite—a site where her secrets were exposed and she was grouped with and defined by what she most wanted to conceal.

Women in fistula centers employed various strategies of fistula-stigma resistance and refusal, such as socializing with other women with fistula, and even reproducing fistula-stigma. Women with fistula often resist moralizing discourse surrounding their illness, frequently expressing anger and evoking religious judgment or condemnation at men who leave their wives because of incontinence. Gomma, 30, expressed that “Because women are broken (*lalace*), most husbands leave, but it isn’t just. It takes two to create this problem [fistula]. Keeping their promises, men don’t.” Rakiya, 30, explained that, “It isn’t right for a husband to leave.¹⁰⁴ It is at his home that she got it. Men who have fear of God (*tsoron Allah*) don’t leave.”

* * *

Driving home from the center as the evening call to prayer echoed through the thick dust that hung in the air of Niamey, my research assistant, Ramatou, and I reflected on the day’s interviews and discussed how fistula affected the lives of women and their social relationships. Ramatou reflected insightfully, “I agree that the main consequence of fistula is shame, but still, it is also used against women. If someone doesn’t like you already, and then you get fistula, they use it as a weapon.” Ramatou validated my own suspicions about fistula-stigma, that fistula is just one more stanchion through which existing relationship dynamics are reinforced.

¹⁰⁴ I asked some women if the situation were reversed, if husbands developed an illness like fistula rather than wives, if wives would leave. Gomma, 30, responded that, “women are more patient and kind than men. If a husband were sick, the woman would stay next to him until his death.” When I asked this question to other women, the responses were nearly identical: no, a woman would not leave her husband due to illness because women are more courageous, patient, or affectionate than men.

Fistula may engender stigma, but this stigma must be understood within a context of power. Women with fistula are often active in the management and concealment of their illnesses, frequently doing so successfully long enough to mitigate the social consequences of incontinence. While fistula is not irrelevant in experiences of stigma, it does not exist within a vacuum. In line with critiques of early conceptualizations of stigma, fistula-stigma cannot be seen as a trait existing within an individual, but rather a negotiated process between individuals within a broader context of power differentials. Thus, processes of destigmatization are equally moored in contexts and dependent upon dynamic relationships and preexisting circumstances. As evidenced by ethnographic narrative, some women experienced swift and unproblematic fistula-destigmatization following corporeal repair while other women did not—their relationships were resistant to change despite their physical transformations.

Women resisted, refused, renegotiated, and even reproduced fistula-stigma in various ways. However, the most common means of resistance to fistula-stigma among women in Niger was concealment, self-isolation, and “passing” as “normal.” Indeed, while fistula is assumed to be a highly visible condition, the majority of women with whom I spoke made significant efforts to conceal their sickness (often successfully) for years or even decades from some or all of their social contacts. In order to pass, women employed strict forms of self-management to conceal any contradicting evidence from community members, friends, and even their families and husbands. Women often concealed both the evidence of their illness (through vigilant self-management) as well as their treatment seeking behaviors (producing alibis for care seeking and absence). Women’s extraordinary efforts to conceal their incontinence and “pass” is explored in the following chapter.

Chapter 12

Concealment and the Art of Passing

Although fistula is often portrayed in the donor and media narrative as an eminently visible marker of a woman's identity, the majority of women I came to know made significant efforts to maintain control over the information others had about their conditions. The global fistula narrative overlooks women's agency in their significant efforts to conceal their conditions from the outside world. Frequently women with fistula invested significant resources of their time, energy, and finances into acts of concealment, transforming fistula into a largely invisible condition, one that could not be easily observed, but often existed in the rumors and gossip of community members, and in the internal shifts in identity of the women with fistula themselves. In this chapter I explore the two-pronged strategy of concealment and self-isolation that women with fistula adopt in order to live with their conditions, the quotidian work of self-management and concealment, and the high price of fistula management.

12.1 Concealment and Working to "Pass"

Useful in thinking about women's concealment work is Lenore Manderson's (2011) discussion of how men and women in Australia with incontinence and stoma bags often resort to virtual seclusion and heavily managed interactions with the outside world in an attempt to control their uncontrollable bodies. Manderson explains that, "People negotiate bodily appearance and representation to minimize the impact of difference of normal and deviant, to live 'normally' regardless of bodily diversity or (culturally defined) deviation, and to work with bodies that inhibit mobility, function and action" (Manderson 2011:67). Manderson highlights

the ways in which managing one's body impedes on personal interactions and renders sustaining close relationships difficult. "Sounds, odors, texture, volume are all given an immediacy that is also a warning: body functions such as elimination can only be taken for granted because they are controlled," Manderson argues, "Out-of-control people must attend to their bodies constantly to prevent greater social disruption" (Manderson 2011:171).

Much like the Manderson's observations of "out-of-control" Australians' unrelenting involvement in strategies of self-isolation, bodily containment, and stigma management to gain control over their leaking bodies, in Niger, women's quest for normalcy in spite of their fistulas through concealing incontinence and "passing" often comes at a cost to their personal relationships, social status within their communities, emotional health, and economic stability. Indeed, for women in Niger, the quest for normalcy requires sacrifice. In this chapter I draw from Manderson's framework, but consider the sacrifices necessary for the quest for normalcy in the poor, polygynous, and patriarchal setting of rural Niger.

Individuals I spoke with often explicitly tried to "pass" as a well person, employing strict forms of self-management to hide any incriminating evidence from neighbors, friends, and some kin. A surprising number of women with whom I spoke explained how through ingenuity and discipline in equal measure they had been able to hide their fistulas from their communities, their friends, their families, their co-wives, and—most impressively—their husbands. Of the 92 women in my sample who explicitly answered the question "have you ever made efforts to hide your fistula?"¹⁰⁵ 68 women (74%) responded that they had while only 24 women (26%) responded that they had never attempted to conceal evidence of their incontinence or manage the

¹⁰⁵ Eight women never explicitly responded to this question. Some of whom were asked but for various reasons did not respond, but most of whom accounted for early interviews before I knew to ask about concealment experiences and strategies.

information about their illness. Many women were quite successful in their concealment efforts (see Figure 12.1). For twenty-one women, only their immediate family or closest friends knew about their incontinence. Several women (6) even succeeded in concealing their fistulas from *all* of their social contacts for months and sometimes several years. Sixty-three women were successful in hiding their fistulas from many—if not the majority—of people. Sixteen women were able to successfully conceal their fistulas from even their husbands, claiming that he was still unaware of her condition.

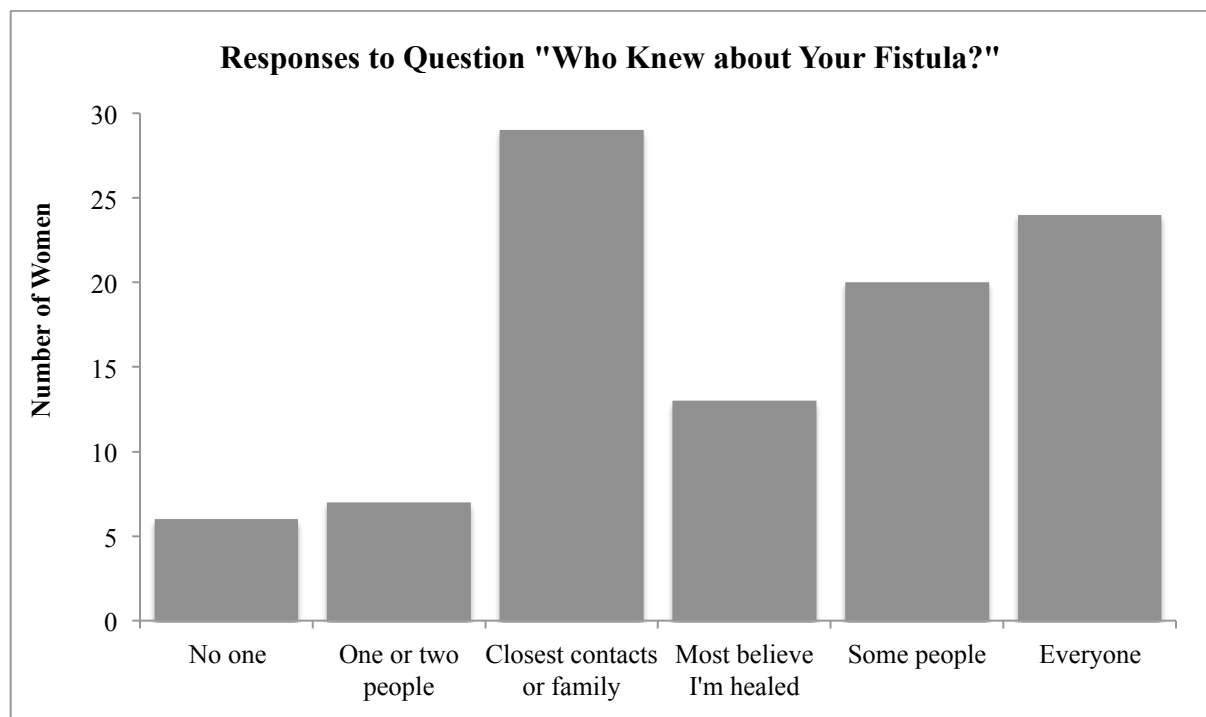


Figure 12.1: Responses to question, "Who knew about your fistula?" among ninety-nine women with fistula.

Although nearly every woman in my sample made some attempt to conceal her fistula (with the exception of women who newly developed fistula and/or had not yet returned home),¹⁰⁶

¹⁰⁶ Although 24 women claimed not to make any effort to "hide" their fistulas from others, many interpreted this question as concealing or actively managing the knowledge of their condition from others (rather than the physical evidence of their incontinence). Even for women who claimed not to have actively hidden their fistula, most still attempted to control the outward evidence of their wetness.

in the extant corpus of fistula literature, the concealment work of women is overlooked.¹⁰⁷ On one hand, the absence of women's concealment effort fits into the global narrative of women with fistula as agentless victims; on the other hand, this absence is surprising considering how dominant themes of concealment are in women's own illness narratives and quotidian experiences.

Strategies to “Pass”

Women with fistula engage in dual strategies of concealment: (1) quotidian changes of behavior, dress, and hygiene in order to disguise incontinence, and (2) more systemic relational changes, modifying the ways in which they engage with their families, friends, husbands, households, and communities. The most common strategies employed by women with fistula in Niger to conceal their conditions are the utilization of fabric pads, high standards of cleanliness and frequent bathing, selective fasting to avoid leaking during important events or during their rotation with their husbands, the careful control of information, and using perfume to cover odors. Additionally, women engage in a spectrum of behaviors of self-isolation, including infrequent departures from one's home, “opting-out” of social commitments and reciprocal relationships, social distancing, physical distancing, accepting marital separations in order to avoid co-wives, and even relocation, moving from rural villages to larger urban towns or cities where they enjoy relative anonymity.

Nafisa, a thirty-year-old Zarma woman, wore her skirt wrapper, which customarily ends at the ankles, extra long so that it covered her feet and concealed any stream of urine that might otherwise be visible on her skin. “In the village there is dirt and dust everywhere. Our feet

¹⁰⁷ Some anthropologists have explored concealment in the context of (non-fistula related) incontinence among women in the Western world (see Manderson 2011).

become grey with it. When the urine runs, the stream is clear on my legs, on my feet. People might stare. So, I cover myself,” Nafisa explained. As well as changing the way she wore her skirt wrapper, Nafisa also switched from the more popular chest-length hijab to a more conservative floor-length hijab in order to hide any visible wetness on her behind. “I don’t want people to see me,” she explained, “I wear a wrapper to cover my feet. I wear a long hijab that I pull up and circle around me when I sit, but when I get up, it goes down around my feet and no one can see the urine. No one can see my backside.”

Like Nafisa, Aishatou, a twenty-five-year-old Tuareg woman, also took special precautions to ensure that her wetness was never visible, “I wore fabric pads in my underwear—I washed the cloth at night and hid them in a sack in my room. If someone comes to visit, I quickly bring [the pads] inside so no one sees them... I need four a day or so. I wash them every day. Every day, every day, really, I’ve tired myself from all the washing!”

Not only did women try to conceal the visibility of their wetness through their dress, but many women attempted to diminish the flow by controlling their intake of liquids. Habi, a seventeen-year-old Hausa woman, explained, “When I am at home, I try not to drink water when the sun is up. But, I try to live a normal life. So, my friends don’t know. No one knows that I leak. At home, the secret is shared only between me, my mom, and my husband.” Habi coupled the reduction of the intake of liquids with protective garments, investing much of her money in extra clothing, typically wearing two pairs of underwear along with two wrappers.



Figure 12.2: (from top to bottom, left to right): A woman with fistula holds her urethral plug, used to manage chronic and incurable incontinence. A woman sits next to the diaper she fashioned from water resistant material originally used for car seat upholstery. Women demonstrate different pads used to manage incontinence fashioned from various materials and folded in order to absorb varying flows.

12.2 Regaining Control through Self-Isolation

According to Lenore Manderson’s 2011 research on women with stoma bags in Australia, women feel infantilized by their uncontrollable bodies, and thus in an effort to regain some control and to avoid embarrassing and emotionally painful situations, they self-isolate:

Loss of urinary control strips women of their social rights as adults. Incontinent, they are children again, increasingly wary of the risks of betrayal by their maverick bodies. Fearing exposure of their inability to control their bodies, women limit their social interactions: how often they leave the house, where they shop, what clothes they wear, and how they manage (or avoid) sexual and other intimate relationships (36).

Manderson describes the management of urinary incontinence for Australian women as “socially isolating, logistically complex, [and] sometimes humiliating” (2011:37). Similarly, I found that in order to limit their risk of leaking publically, most women reduce the time outside the house to

a minimum and generally avoid social events. The degree of a woman with fistula's socialization in Niger generally extended only to the group of people who knew about her condition and to public events that were limited in the amount of time she was expected to spend there. Rather than being subject to overt discrimination by their communities, most women with fistula retreated from society of their own accord.

Like Hadiza (16, Hausa), many women explained, "I don't go anywhere. I was always at home." Sahara (19, Zarma), specified, "With this sickness, you can't go anywhere—not to baptisms or weddings. You can't spend time with people because when you sit and then get up, everyone sees you are all wet and that is very shameful." When I asked Mida (37, Songhai) if she felt that she was confined to her house because of her fistula, she responded, "No, it is my choice. I don't leave the house because I don't want people to look at me. But, it is my choice." Raha (55, Hausa) explained that she rarely left the house and when she did, she went mostly into the bush where there were no people, "I don't want to be around them. I don't want them to look at me and ask each other, 'Is she wet? Does she smell?'" Tandahamed (18, Tuareg) told me, "I don't go out. I am always at home." When I asked her why, she explained simply, "I don't want people to know that I leak, and if I went out, they might smell me." Safia (27, Hausa) explained, "Women with fistula avoid going near other people. It is the women themselves that don't want to approach people. They are afraid that they smell bad." Women with fistula felt most comfortable when they were able to both socially and physically distance themselves from community members and sometimes even family members. All of these women expressed a similar sentiment: staying home and self-isolating from others provided them some distance from the anxiety, shame, and humiliation they might experience if others saw them leaking or smelled their urine.

Women with fistula engage in systematic social distancing, often “opting-out” of social commitments and reciprocal relationships in order to protect their identities as “well.” Women are reluctant to leave their homes for any extended period of time for fear of leaking publically, and thus women begin to neglect social obligations, such as attending marriages and baptisms or other social events in the community, or visiting friends.

Another strategy that women deploy in order to conceal their fistula is relocation, often moving from small villages to larger towns or cities where they can enjoy some anonymity. Mida, a thirty-seven-year-old Songhai woman originally from Mali, explained that back home, everyone knew of her fistula, which was not the case in Niamey, “because I don’t go out much here, and I was never very sick here, very few people know.” Mida, who was separated from her husband, had made the decision to leave her marital home where her co-wives were “very curious” about her condition in order to keep her secret, “my husband would never have told anyone about my sickness, but his two wives, no, I did not trust them, as soon as we had a fight about something, maybe they would turn their backs and tell someone in the village. Then everyone would know.” Indeed, not only does the relocation from rural villages to larger towns offer more opportunities for involvement at clinics (including surgical intervention, but also including training sessions, courses, and economic opportunities such as the involvement in special projects which offer funding to women living with fistula), but women also have more freedom to control the information about themselves amidst the anonymity of a large town.

Women’s experience of fistula is largely defined by small (but daily) acts of self-segregation. Women often reported moving rooms in the same house (sharing a room—and

sometimes a bed—with an older or younger female relative, rather than their husbands),¹⁰⁸ designating a mat for themselves to sit on rather than sharing a sitting mat with others, or positioning their mats further from others in the household, or purposefully downwind. Interestingly some acts of self-segregation, such as the decision to eat-alone, raise interesting questions about chronic illness in Niger. Of the women who reported eating alone, many did so not because “fistula” constituted a special illness category that was beholden to strict rules of purity, contagion, and confinement, but rather because eating alone is a common practice for all types of illness in Niger. When I visited Mida, a thirty-seven-year-old Songhai woman who had lived with fistula for seven years, in her home she explained, “I eat alone not because I cannot eat with others, but because when someone is sick they are allowed to rest and eat while reclining in their rooms.” Indeed, I witnessed this frequently when visiting people in their homes in Niger. Particularly older family members who were ill would have their meals brought to them, apart in a single-serving dish, where they were free to eat at their own pace while resting in bed. As fistula is presented as an acute illness, the long-term (and potentially slow-acting) implications of chronic fistula are under-examined. The allowances provided to chronically ill individuals to unburden themselves from various social obligations might simultaneously act as a mechanism for the deterioration of social bonds while also reflecting the strength of those bonds between caretakers and ill family members who are unburdened from social obligations.

12.3 Learning to “Pass”

Due possibly to amenorrhea caused by frequent pregnancies, extended periods of lactation, and potentially even severe anemia (quite common among women in rural Niger),

¹⁰⁸ It is important to note that of the women who did not live with their (sometimes quite supportive) husbands, most others lived with their parents, grandparents, siblings, aunts, or uncles. Of the women I interviewed, not a single woman lived alone.

many women with whom I spoke did not have extensive experience managing their menstrual cycles. Although some women did use folded cloth to control their bleeding, many others told me that during their periods, they would bleed very lightly, necessitating only an extra skirt wrapper (*zane*) or a pair of underwear (*wando*) to manage their flows and prevent blood from becoming visible. When these women developed fistulas, they lacked the experience of managing constant vaginal flows, and often did not know how to make cloth-based pads. For these women, it was only at hospitals that they learned how to tear cloth into long strips, fold them into thick pads, and tuck them into underpants or fashion them to belts. It was during women's first experience at fistula centers that they observed more experienced women's strategies for managing their incontinence, slowly adopting them themselves. Nana, a thirty-two-year-old Tuareg woman who had lived with fistula for seven years, explained that her period was never heavy ("it didn't run much"), so she had no experience making or wearing pads:

I never wore anything when my blood ran, because not much came. So when I began leaking urine, I didn't know to wear anything either. It wasn't until I came to the hospital that I was taught to wear cloth. They instructed me to fold up fabric and wear underwear so that transportation from home to the center would be easier.

Indeed, it is at fistula centers that many women learn strategies to conceal their conditions. In February of 2013, I sat with several women in a dormitory on the hospital grounds. I asked about management strategies, and I was privy to a showcase of ingenuity. Women brought out cloth, towels, foam stripped from couch upholstery used to make pads, and plastic sheeting or stitched-together plastic bags that they used to sleep on or to make water resistant diapers. Women share among themselves strategies they learn and adopt from various fistula hospitals across Niger, Nigeria, Burkina Faso, Benin, and Togo. In places with limited resources, women innovate solutions, creating their own "appropriate technologies" for incontinence management and concealment. These strategies are passed from woman to woman

in centers across West Africa, traveling from one center to the next as women migrate across regions, and often across borders, looking for a cure.

Although women with fistula have conceived of many innovative management solutions to incontinence, the most ubiquitous strategy—used by almost every woman in my sample—was the utilization of fabric pads. One woman explained the nuances that differentiate pads used for menstrual blood from pads used for incontinence: “For blood, the cloth is smaller, only about half the size of the cloth used for urine. Also, it is more tightly rolled.” Another woman explained how those with more experience (typically older women) preferred to wear pads without underwear (as the tight leg bands can excoriate the delicate skin of the inner thighs), demonstrating (amidst much laughter) her ability to walk freely with a pad deftly lodged between her thighs. The nuances of fabric pad construction, utilization, and hygiene is learned among women in centers, sometimes through direct teaching, but most often through junior women’s observation of more senior women’s daily management techniques.

Additionally, in the centers women reinforce expectations of “normalcy” and urine/fecal management amongst themselves, punishing breaches of these expectations through insults and gossip. Balkisa, a forty-six-year-old Zarma woman whose narrative of tireless self-management is told below, explained, “God made people differently. Some people neglect themselves when they are sick. Others aren’t lazy—they do everything for themselves.” Indeed, many women like Balkisa who judiciously managed their bodies believed women with fistula who allowed themselves to smell like urine or leave behind visible wetness were “lazy,” “dirty,” or “without pride.” The assumption was that women with fistula who allowed their fistulas to become visible either through sight or smell must have been dirty and complacent about their self-presentation *before* their illness. Although such an assumption is rather unforgiving, it is true

that during the months I spent with women at the various clinics, very rarely was the smell of urine detectable. Women who had recently developed a fistula, and often still suffered from leg paralysis from foot-drop (and thus limited mobility), were the only ones whose odor was ever noticeable. To say a woman smelled of urine was among the cruelest of insults lanced between women at the center.

Balkisa's Story—Commitment and Sacrifice to “Pass”

Balkisa, a forty-six-year-old Zarma woman, had lived with fistula for twenty-nine years. When she was eighteen, she developed a fistula following her first pregnancy. She was able to manage both her fistula and her marriage, continuing to have six pregnancies following the pregnancy that resulted in fistula (however, all seven children were stillborn). Balkisa spoke a few words of French, considered herself fairly cosmopolitan, and commanded some respect among her roommates at the fistula center. She spent her days washing her cloths and bathing several times a day. Her cleanliness was a source of friendly teasing and some admiration among the women at the center. At the time of her interview in September 2013, Balkisa had already undergone six failed previous surgeries and had been at the fistula center for 18 months. She explained to me the ways in which she attempted to control her incontinence over the past three decades:

When I remarked that I couldn't hold in urine or go to the toilet, I knew that there was a problem. I used old fabric and I cut it into strips, putting it between my legs to soak up the leak. I used perfume so that no one knew, so that no one could smell me. As soon as the fabric was wet, I'd change it out with a dry piece. I was always washing the wet cloths. Not everyone knew that I leaked. Really, most people did not know. I don't let anyone know that I am sick... Now I've hid it for over 25 years. Only my close family knows—and even them, they don't see it with their eyes. We eat together, and we talk together. They know that I had a problem, but they can't see the problem.

Even at night I use a plastic sheet and put cloth on top. I never allow urine to run in my room or wet my things. Around four in the morning I wake up before others awake, I wash all of my cloths and dry them. I use perfume and also incense on the cloth, my body, and my room. If someone is touched by this sickness, if she cares for herself,

she won't have any problems with the person she lives with... I don't like to be dirty, so this fistula is a problem. I have no power over it. I suffer, but I force myself. I never tire of taking care of myself—I never let up. I never let myself sit with urine on my body or clothing until I smell.

Many people congratulated me because they thought that I was healed. “She returned from the hospital and she is healed!” That's what people say. If they congratulate me, I say, “Thanks to God! Thanks to the surgeon.” No one talks about my sickness anymore. I don't think anyone knows now...

I never throw away fabric and now I have so many, so even during my periods, I don't let even a single drop redden my skirt. I wash and I wash... I am not as careful to hide it from my close family because I know they won't reject me—they won't be disgusted by me.

My husband has asked me to return to Abidjan [where he now lives], but I said that I couldn't. I can't do two things at once. I can't both take care of myself and take care of a household. When we were together, I took care of myself and he never made a comment about [my fistula]. Not once. Because I took care of myself, no one could smell anything. Because it didn't leak to my feet, no one would see... I don't feel mistreated. I eat, sleep and chat with people. People tell me that I smell good. People even say that they want the perfume I use; they ask me where I buy it!

The theme of personal diligence permeates many women's self-narratives, taking form in tireless pre-dawn washing of pads, conscientious hiding of soiled pads, selective fasting of food and water, and careful personal hygiene—strategies that all come at a cost to women's personal relationships. Here, Balkisa explained how through strict self-management, she was able to gain some power over her body, which, in its perpetual incontinence, was marked by the lack of control. Clearly, however, concealment had come at a cost to Balkisa, whose social relationships (particularly with her husband) had been deprioritized. These social consequences borne from concealment will be explored later in the chapter.

12.4 The Presumption of Cure and Continence

Balkisa's story demonstrates another important theme of women's illness narratives—the assumption that women are “healed” following their return from hospitals where they underwent their first surgeries. Many women admitted that at the onset of their fistula, concealment was difficult, if not impossible: “fistula is not an illness you can hide” (Amina, 37, Fulani), “everyone

who had ears knew I had it” (Raha, 55, Hausa). For women like Amina and Raha, it wasn’t until after their first departure from their villages for fistula treatment centers that they learned the art of “passing.” The ability for women with fistula to “pass” as healed upon return home from initial visits to fistula centers is due to two factors. First, women learn concealment strategies from others women with fistula in informal networks of information sharing at fistula centers. Second, individuals in a woman’s community are unaware of possible (or even probable) poor outcomes of fistula surgeries and thus many presume that women are healed upon return from hospitals, particularly when these presumptions are corroborated by a woman’s lack of visible wetness (due to concealment strategies learned at centers).

Because obstetric fistula is most often the result of a birthing complication, which often was nearly fatal, directly following an obstetric catastrophe, a woman’s list of bodily complaints is often quite long. Many of these injuries may be more painful, worrisome, or urgent than the fistula. Women may have trouble walking, may experience residual bleeding or infection, and may have intense pain. As Kalthumi (31, Zarma) said, “I did not know if I would live or die. I was very sick then. I wasn’t too concerned with the leaking [of urine] yet.” In the face of myriad health problems, the management and concealment of incontinence is often impossible and frequently not a top priority of women or their families.

Indeed, this period directly following the onset of fistula is a particularly vulnerable time for women because, due to illness, they are typically cared for by family members and largely incapable of self-regulating. Because it is typical in Niger for neighbors, family, and community members to pay visits to individuals in the community who fall ill, it is when women are least capable of self-regulating or concealing their fistula that they are often most exposed to those to whom they are least close. Unsurprisingly, it is during this period of postpartum illness and

recuperation that community members usually learn of women's injuries. As Aissa (26, Hausa) explained, "If someone comes to see you during your sickness, they will see that you are wet. When they leave, they tell one person. That person will tell one person, and soon, everyone knows." Many women looked back on this period with some resentment, recalling visitors who they suspected came not out of compassion, but curiosity. As Nafisa (30, Zarma) explained:

It isn't a sickness you can talk about. You don't want a single person to know about it. If people in your village suspected you had it, they would do everything to come and see you, then to gossip. With me, some people came to visit me. They took their time; they sat for a long time. I knew that they were only waiting for the moment when I got up, they were waiting to see if the rumors were true, if I was wet.

Typically, it is only after women regain their strength that they become capable of managing their urinary (and/or fecal) incontinence. The rupture marked by a woman's departure from her village to a hospital offers a woman the opportunity to refashion herself. Although this refashioning often is not physical (as the rates of surgical success are low, as discussed in chapter five), it is a transformation of the exterior. When a woman returns home, community members may remark upon the visual cues of cure—dryness, reestablished strength, and often weight gain. Profiting from a certain mystery which envelopes the biomedical world in many Nigerian villages, some women either opt not to correct others' assumptions regarding the restoration of her continence, indirectly validating their assumptions about her repaired body, or are active in furthering such assumptions, directly claiming to be cured.

Following the development of her fistula, Rabi, a forty-year-old Hausa woman who lived with fistula since she was eighteen years old, continued to live happily with her co-wives and husband (birthing eight more children, four of whom survived). With the exception of her mother, Rabi concealed her fistula from everyone (including her husband) for over a decade. "In the beginning, people knew that I was sick," she explained, "I went to the hospital, and when I

came back, I wore pads to hide the leak. And now people don't think that I have it anymore. They don't understand why I am back at the hospital now." I asked Rabi if people asked her if she was healed, or if through concealment strategies she was able to convince people that she no longer leaked. She explained that because most people are too polite to ask her directly if she is healed, she is not often in a position where she has to directly lie about her health status:

If you go to a baptism, people will look at you. Those who visit you stare at you, looking at your feet and your back to see if you are wet or not. And, really, no one but my husband would ask me directly if I was healed. It isn't a polite question. But if they asked 'How is your health?', I would say 'I have health!' (*Lahiya lau*).

Admitting that her deception was sometimes more direct than indirect, Rabi began to laugh a bit, "As for my husband, when he asks, I just tell him that I'm healed. '*Alhamdulillah*' (Praise God) I say."

When Safia (27, Zarma) first developed a fistula, she was incapable of self-regulating. "In the beginning I was so sick so couldn't manage it," she explained. Safia described how difficult her life had become because of her sickness; she suffered from constant anxiety and some depression because of her perpetual incontinence. "Before when it was bad, people wouldn't come in to my room—they would stop at the door to my room and ask how I was. Only people very close to me would come in and sit down. They smelled my urine and did not want to be near me." Safia eventually employed several strategies to conceal her incontinence, but it was not until she left her village for the fistula center that Safia was able to "pass." Although "everyone" initially knew about her illness, Safia was eventually able to engage in passing work, capitalizing on the lack of understanding of biomedical and the etiology of fistula in order to pass as healed after her return from the fistula clinic, even though her surgery did not succeed. Safia claimed that most people in her village believed that she was healed and only her closest friends and a handful of her female relatives knew the truth. "Now that my neighbors

think I am healed, life is easier. It is better. I only fear that they will one day learn my secret and life will become hard again.”

12.5 Concealment Capacities

Not all women’s conditions, however, lend themselves equally to being concealed. A woman’s ability to conceal her fistula may depend on various factors including the severity of the condition, the type of fistula, local customs following the onset of illness, household spatial configurations, and the number of co-wives and husband rotation patterns. A woman with a large fistula or extensive damage may have a more difficult time concealing her fistula due to the severity and persistency of her incontinence. A woman with a smaller vesico-vaginal fistula or residual incontinence, however, is often capable of concealing her condition for extended periods of time. Nana (32, Tuareg), for example, hid her fistula from even her husband for seven years. But with her eighth pregnancy, the fistula increased in severity, making it more difficult to hide. It was not until this point that she decided to seek care:

No one knows about it, only my mother. I’ve never told my husband. I’ve hidden it from him for all seven years... The nights my husband sleeps in my room, on the fifth day,¹⁰⁹ I don’t drink fura¹¹⁰ or water. I limit what I take in. Then it doesn’t run much. Before my eighth birth, the birth of Amina [her one year-old] my condition wasn’t so bad—it was easy to hide, but with the birth of Fati, it has gotten much worse and much harder to hide. Before, if I was laying down, the urine didn’t run much. The flow was minimal. Before, I could even walk around a little without it running. Before, I changed [my skirt wrapper] twice a day—I’d get up and pound millet and wear the same wrapper until 2pm, then I’d change and put on another. I didn’t wear anything [pads] because I didn’t know how to use or wear one until I came here [to the clinic].

If I leaked, I would hold a baby and my co-wives would think that every time a baby pees on me, I change. They probably think I am cleaner than they are. If they knew, they might tell my husband to divorce me. They might say, “The woman you love is sick—how could you love her more than us?”...

¹⁰⁹ There is a six day rotation between the three co-wives, each woman spending two consecutive nights with their husband.

¹¹⁰ A millet and milk based porridge that many people in rural Niger eat for both breakfast and lunch.

After Amina, it became too difficult to hide. So, in order to come here [fistula repair clinic], I told my husband that some spot had come out in my [vagina] and that I needed to get it treated. He accepted. He allowed me to come to the hospital for medical care. Now when he calls me, he asks if I am being treated for the spot. I tell him that they have to give me medicine every two weeks, and to go home in between the two weeks—well, it wouldn't make sense—it is too far and would take too long and cost too much. So, he agreed that I should stay here until the treatment is finished...

When I go home, to avoid having sex with my husband,¹¹¹ I will say that because of the C-Section I had last year, I can't do hard work and can't have sex, otherwise the C-Section will reopen. This way, I can follow the advice of the doctor without having to tell my husband about the fistula.

Nana was able to hide the fistula for seven years because it was not very severe—she did not leak all the time, and her incontinence was not particularly noticeable. This might explain why Nana never tried to get another reparative surgery—operations are an economically and socially costly pursuit which can take women away from their homes for many months and threaten their identities as a “well” person back home. But, with the birth of her baby, the fistula became much worse and the cost/benefit analysis of seeking care changed—continuing to hide her fistula became too costly.

Although co-wives often pose a risk to women's concealment efforts, Nana might not have been able to conceal her fistula for seven years had it not been for her two co-wives. She took advantage of the six-day rotation between the three wives, which allowed her four non-fast days followed by two fasting days during her rotation with her husband. If she did not have any co-wives, or even if she had only one co-wife, her ability to fast continually or with fewer breaks would have been difficult, if not impossible. Additionally, one of Nana's concealment strategies capitalized on the reproductive success of her two co-wives, using babies as scapegoats for her wet wrapper.

¹¹¹ A period of six months' abstinence is suggested for women following repair surgeries so that delicate closures do not reopen.

Nana's concealment strategy also took advantage of the limited biomedical knowledge available to people in her village, first by crafting an alibi for care seeking, and second through strategically blaming her post-surgical required abstinence on problems incurred from her previous C-Section (for which many reproductive and gynecological problems are commonly blamed among Nigeriens).

Additionally, for most women, recto-vaginal fistula (RVF) is easier to conceal than vesico-vaginal fistula (VVF). Women who can avoid loose stool (achieved through a variety of measures, particularly dietary restrictions of excess fat, fruit, and fibrous vegetables) only experience the consequences of their RVF occasionally, often restricted to daily bowel movements (when the stool is evacuated through the vagina rather than the rectum). Although women with RVF are at a high risk of infection (and thus odor), the management of RVF appears simpler than VVF, which may leak persistently. Indeed, Louisa, a twenty-three-year-old Tuareg woman lived with recto-vaginal fistula for three years before even realizing that she was ill. When I asked her who knew about her fistula, she responded, "I didn't even know. Who else could?" She explained:

The baby was too fat (*kato*), so I was told to push hard. I pushed hard, but when the head came out, he was stuck at the shoulders. The midwife pulled and pulled with too much force. She tore something inside of me. After forty days, I noticed that when I had diarrhea, it came out the wrong hole. It leaked a lot and I couldn't hold it. It was the same when I had gas—I couldn't hold it, it would pass from both my anus and vagina. Also, a liquid was coming from my uterus and it smelled so bad.¹¹² It smelled like an infected wound. I wasn't concerned with the fistula—I didn't even know it was there, but I was very concerned with the liquid that came out from my uterus. The smell was so nauseating. Because the liquid smelled very bad, I washed all of the time and used perfume. So, even the women in my house didn't know.

I took some medicine, and the liquid stopped and I was fine for a time, but during my second pregnancy the liquid started again and ran a lot. When the baby was big in

¹¹² According to the National Institute of Health, symptoms of recto-vaginal fistula depend on the size and location. Frequent symptoms include the passage of flatus or liquid stool through the vagina. Additionally, much like Louisa's complaint, the NIH explains that patients may complain of "a malodorous vaginal discharge and recurrent vaginitis" (deBeche-Adams and Bohl 2010).

my stomach, there was so much liquid. It was only three months ago that I went to the Maternity and they told me that I had a problem of the anus. Before then, I didn't hurt, so I didn't know that I was sick. It was just the liquid that concerned me. I only came to Niamey because I live with my husband in [northern Nigeria] and now there are too many problems because of Boko Haram. I was scared and came here to get away from the violence and to visit family. I came to the hospital only because I was already here.

Louisa never made efforts to conceal her fistula because she did not know she had one. She sought care for what she believed was an infection only because she was already in Niamey visiting family. When I asked Louisa if she thought RVF was easier to manage than VVF, she agreed that it was, explaining:

When it is [RVF], if a woman is clean, no one knows she has it—not even her husband. It isn't every day that I leak, maybe only once per month when I don't eat well. So, I just wash and it is finished...If the fistula is all the time—if a woman is always leaking, that can worry her until she is driven to tears. If I leaked all the time until my husband commented, I would be really worried too. For some women with fistula, urine runs like water—when they walk, all the time. But some can also manage it with a pad and no one knows. So, it depends on the amount she leaks if the woman will be really affected.

Additionally, local customs following the onset of illness, which vary widely between villages in Niger (even within ethnic groups), can either complicate or facilitate concealment strategies. Nafisa, a sixteen-year-old Zarma woman, had concealed her recto-vaginal fistula from everyone but her mother and father (including her husband and his family) since she developed the injury several months before. Her mother instructed her to conceal her incontinence, “She said to me that if I told people, they would gossip and never let me forget it,” so her mother told their neighbors that Nafisa had a “stone in her stomach.” Due to a custom in her village whereby new mothers are hidden behind a curtain until the post-partum period has finished, Nafisa was able to escape from the curious eyes of her neighbors and in-laws, protecting herself throughout the vulnerable post-partum period when many women's illnesses are often revealed to visiting community members.

Still, Nafisa confided that shouldering the burden alone was difficult, “It is hard if you have something that you can’t say out loud. You can’t say the words to anyone. It is very hard.” But, unlike ninety percent of women in the sample, Nafisa’s child survived the labor.¹¹³ Looking down at her infant daughter with a smile, she said, “But when my daughter grows up, I will tell her about what happened when she was put into the world. I know she will keep my secret.”

Finally, the spatial configuration of a household may also impact a woman’s ability to conceal her fistula. Rabi, the forty-year-old Hausa woman who hid her fistula from everyone (including her husband) for over a decade, explained that her living situation was particularly conducive to maintaining her privacy, and thus, her secret: “I am clean and I have my own room,” she explained, “My co-wife has a room, and my husband has his own room too.” She rifled through a cement bag filled with her belongings in the corner of the room, pulling out several washcloths. She folded the cloth lengthwise in fourths, explaining:

During the day I put the soiled cloths in a tub that closes tightly. It has a lid, so the smell can’t get out. I keep it in my room, where no one can see. I use about six cloths a day, if I drink *fura*. I don’t take them out of the tub during the day. I have my own shower behind my room. Each of us, me, my co-wife, and my husband, we have our own showers. So, at night, I wash them all and hang them to dry in my shower. At first prayer I take them and fold them, cover them in perfume, and hide them in my room again without anyone seeing me.

For Rabi, the particular circumstances of her living situation—particularly her own room, her own shower, and two co-wives with whom she shared rotations with her husband—enabled her to conceal her fistula. I asked Rabi how her regime changed during the nights she spent with her husband. She explained that five years ago, her husband took a third wife. Then, she only slept in his room every four days. This made it easier to conceal:

¹¹³ Only 10 children (of 105 births) were reported to survive the labor that caused fistula. In the sample, 85 babies did not survive (5 fistula in the sample were not from labor and thus are not accounted for, and 10 women had recidivistic fistula, making the total 105 births).

When I sleep in my husband's room, I wash all of [the pads] first and hang them to dry, then I wash myself, and then I go to him. Every four days I clean my body very well. I am sure not to drink water or fura during the day. I only eat food (*tuwo*) without sauce. If I don't drink, it won't run. If I'm not going to his room, I eat well and I drink well and it is easier on my body.

Like other women, through relentless self-management, Rabi was able to live as an integrated part of her community, garnering respect among her neighbors and friends. She explained that attendance at community events was an important part of being respected within one's community, so, despite the risk to her identity as a well person, she always attended, "If I leave the house to go to a marriage or baptism, I do everything to hide it. But if it is far and I have to sleep the night there, I will change the pad where no one can see, wash it, and dry it where no one will see—in a field or the bush. Or, I will dry it in a shower that many people use, then they will think it is a baby diaper." Rabi explained that despite the high price of passing, it was worth it:

It is a secret, only my mother knows. She is still surprised that I have been able to keep it secret for so long. She said to me 'all of those years you've been able to keep it a secret and your husband doesn't know!'... It is hard to keep a secret like this because I am always thinking about my body. If people knew, they might treat me badly because I am the only one with this sickness... Women with this sickness, their lives are better if they hide it.

I asked Rabi why she decided to hide it for so long; if she was afraid that people would mistreat her. "Yes!" She responded, "And I was ashamed. My husband knew of my fistula in the beginning, still he made the decision that I should come back to his house. Still, no one can stay with that kind of dirtiness—one day, even if your husband loves you, one day he won't be comfortable with you." After hearing of Rabi's diligence and commitment to her concealment, I asked her if it was difficult to have such a big secret. "Yes, I am always worried (*ina jin damuwa*). I sometime want to tell someone about it, to share the secret, but I am too afraid. Once one person knows a secret, they often tell."

12.6 Consequences of Concealment

As Rabi's sentiments of worry and fear reveal, these management strategies are not without consequence—social, emotional, and physical. Not only does strict vigilance over one's body require energy often redirected from social relationships, cause intense anxiety and feelings of isolation, but the utilization of cloth pads to control the flow of urine frequently results in irritation of the inner thighs as moist and acidic cloth is in constant contact with women's sensitive skin. Several women explained how using pads results in chafed thighs, some demonstrating the discoloration of their inner thighs that had become black and ashy due to the constant contact with the urine-soaked cloth. At best, these pads result in irritation, at worst, they excoriate tender skin, causing open sores that are prone to severe infection and unremitting pain. Thus, women are left to balance these negative consequences—visible leakage, or invisibility but pain. As a result, some women (usually women who were not living with co-wives and thus experienced more freedom in their own homes) prefer not to wear pads when at home, reserving them only for when they needed to venture beyond their compound's protective walls. For example, Nafisa (30, Zarma) only used pads during the day, leaving her inner thighs time to heal at night. To keep her dry at night, she dug a hole underneath her sleeping mat and placed a basin in the hole to collect the urine that ran during the night.

Due to the risk of infection posed by the use of fabric pads (resulting from open wounds on inner thighs), there is some clinical disagreement at the centers about the use of fabric pads. Some clinicians exhorted women not to use the pads, using instead small pots to catch urine flows. Other clinicians encouraged their use, even teaching women how to use the fabric pads in the first place. Alternatively, women received mixed messages from clinics, told not to use pads,

but simultaneously given a handful of disposable sanitary napkins (which most women attempted to wash and reuse) from Western donors.

Women's utilization of selective fasting can also result in serious health problems. In an attempt to diminish the quantity of leaking urine, some women restricted the quantity of liquid (and sometimes food) that they consumed. In Niger, when temperatures soared above 100 degrees Fahrenheit much of the year, women who chronically restricted their intake of water could suffer from chronic dehydration. Dehydration (in conjunction with infection and diets low in protein and vitamin A and B, but high in fat and salt) commonly resulted in the formation of bladder stones, or crystallized masses of minerals found in urine. Bladder stones caused women abdominal pain and painful urination (and could cause more serious health problems as well), and often had to be surgically removed before women were able to undergo fistula repair surgeries—further prolonging their stay at fistula centers.

Additionally, concealment work has many emotional consequences, causing loneliness, worry, and anxiety. For women who conceal their fistulas, the quotidian work involved with concealment often takes up a large proportion of women's time and energy. I spoke with Ade (40, Hausa) who had hid her fistula for 15 years from everyone. Fifteen years of waking up at three in the morning, sneaking out of her room where she could secretly wash the rags she used as pads, hanging them up to dry, lying nervously in bed, and sneaking back out to take them inside and bathe them in perfume before anyone else in the household woke up for the first morning prayer. Fifteen years of vigilant self care. Fifteen years of new hiding places for soiled rags. Fifteen years of fasting during her rotation with her husband.

I was astonished by her vigilance, an awe that I did little to dissimulate. A slight smile started at one corner of her mouth and crept towards her ear. The more surprised I seemed, the

faster it spread. My eyebrow raised, and I ask her if she wasn't a little proud of her abilities to hide it. She chuckled, "Yes. Not everyone could, you know." I asked Ade about quotidian investments, the long mornings full of angst, and the loneliness she must have felt keeping such a big secret from everyone she loved for so long. The smile began to recede towards center of her face, and soon it was gone. "Yes," she said, "I feel loneliness" (*Ina jin kadaici*).

In compounds where as many as twenty or thirty people live together, and friends, family, neighbors, and village kids come and go, rarely is one physically alone here. Yet, when such a large part of one's identity is hidden away, a woman with fistula often feels alone and socially isolated from others in the compound. Hence, the importance of passing, as Ade explained: "To look like everyone else, to seem like everyone else... I'm not a woman anymore ... But, to others, I look like one." For Ade, loneliness was a small price for passing. "This disease comes from God. But, why give anyone reason to talk. Because people *do* talk." However, for women like Ade, concealment work replaces the experiences of shame and potential or feared mistreatment associated with fistula with the emotional toll of isolation and anxiety. Women who "pass" must live dual lives, emotionally alone with few friends to share their secret, and physically alone, as the social ramifications of concealment are often the weakening and reduction of social ties.

As discussed above in reference to the weakening of reciprocal relationships, the social consequences of concealment work can be severe. Women who are able to conceal the symptoms of their fistula (most notably incontinence) are able to enjoy invisibility, escaping the "sick role" as described by sociologist Talcott Parsons (1951). As explained by Parsons, because sickness often permits a sufferer to assume a role of "sanctioned deviance," allowances are made whereby the sick individual can avoid the responsibilities and obligations expected of non-sick

members of society. Through concealment, women are able to avoid the “sick role,” and women’s relationship to their illness becomes a largely internal process, whereby they struggle internally while attempting to appear “normal.” Yet, there are consequences to such a tradeoff (appearing normal while managing and concealing sickness). Rather than appearing social deviant through a sanctioned means (illness), women who conceal their fistulas often appear socially deviant, as they cannot fulfill attendant social obligations. Aissa, a twenty-seven-year-old Zarma woman, explained that because of her fistula, she was reluctant to leave her home for any extended period of time (fearing that her pad would become saturated and that she would begin to leak or smell). Because of her unwillingness to leave home, she began to neglect social obligations, such as attending marriages and baptisms, or visiting friends. As a result, the strength of these connections attenuated over time:

With this sickness, I don’t go out much. If I do go to a friend’s house, I won’t stay long. I will just greet her. My friends, they say that ‘Aissa, she doesn’t like to visit anymore.’ They gossip about me because of it. But only I know why... Because of it [My friends] don’t come very often anymore to see me. If you stop visiting someone, that person will visit you less.

Similarly, Habsu, a forty-five-year-old Hausa woman with fistula, explained that because all of her money went to perfume, soap, and new cloth required for the proper management of her fistula, she had no more money left to participate in gift exchanges, “Because I have no money to give gifts at weddings, or baptisms, or to send meals to neighbors when I cook something well, people have stopped giving me things too.” Mida, a thirty-seven-year-old Zarma woman, explained that, “Before fistula I had many friends, but now I am not comfortable leaving the house. Sometimes they still visit me, but people tire of coming to see me when I never go to them, so now they come less.” Indeed, due to the energy and exigencies required of fistula-management, women like Aissa, Habsu, and Mida were able to partially regain control

over their bodies and avoid embarrassment in public situations, but then could not fulfill the demands of reciprocal relationships and thus suffered the consequences of weakened social bonds.

Mselle et al. (2011) discuss the effects of social isolation of fistula in Tanzania:

Women living with obstetric fistula experienced lack of invitation to participate in the social economic activities and thought that it was largely because of the bad smell, which prohibited other people to interact with them. Many lost their jobs and could not gather with the rest of the society in social events. This is in agreement with results found by others. As a community member in Tanzania, culturally it is a norm and a commitment to take part in communal events such as wedding and funeral ceremonies. Failure to fulfill these social obligations is considered a serious breach on the basic social principle of reciprocal relationships and may lead one to be rebuffed by the community.

Although my findings agree with those of Mselle, I argue that it is not because of a woman's fistula per se that she is "rebuffed by the community," rather she may be rebuffed precisely because she fails to embody the "sick role," and thus her deviant behaviors are no longer socially sanctioned. Indeed, while women who "pass" may be insulated from the social and emotional consequences of their public incontinence, they are exposed to the social repercussions of failing to engage in reciprocal relationships and failing to meet community expectations for proper social behavior.

* * *

I spoke with an administrator at the Danja Fistula Center who was present when *New York Times'* Columnist Nick Kristof came to interview women with fistula (for the column quoted at the beginning of the introduction, "Where Young Women Find Healing and Hope"). This administrator (who translated for Kristof) recounted how he was interested in speaking with the youngest women who had the most "powerful" stories. He chose to speak to one particularly young and beautiful girl; however, he became frustrated with her answers, aborting the interview and ultimately never using her story:

He was speaking with this woman who had fistula for maybe a year. He asked her “what did your husband do [to you because of your fistula]?” and she said “My husband didn’t drive me away.” “Why?” he asked. She said, “Because my husband didn’t even know!” She was hiding it. One day, she said to her husband, “I need to go out and get help,” so she left the house... She had RVF and VVF and the husband didn’t know, not even talking about the community! ... He kept pressing that with the lady—the girl, but she kept just saying, “nobody knew”... He kept asking, “Did people laugh at you?” I understand; it is normal with interviewers, they try to ask the same question from different angles. But the girl kept insisting, “No, no one knew!”...

He asked that same question four or five different ways. He asked how her husband mistreated her, how the community laughed at her, if she was scorned and laughed at or stigmatized. She kept saying no. She said, “No, I was at my husband’s house. I was never thrown out.” She said no one knew. He didn’t believe it and asked how she could hide it. She said that she kept herself clean and washed herself and her pads. She said that she would wash herself and replace the pad with a clean one. She did it for two or three months before she left for help. She said that when she left her husband’s house, he didn’t know why she left. She didn’t tell him—she just said that she wasn’t well and needed to get help... But, [laughs] he’s not interested in that story, so we didn’t stay long with this particular girl. We only stayed about ten minutes. He interviewed her and he didn’t use her story because it wasn’t what he wanted.

Indeed, reporters, fundraisers, and researchers are all burdened with the onerous task of crafting a generality—a handful of stories (or sometimes just one story) that best represent the amalgamation of all stories. When Nick Kristof heard this woman’s narrative, perhaps he dismissed it as “exceptional,” a case that failed to represent the norm. And while many women quoted in this chapter are exceptional in their steadfast self-management, I argue that small (but daily) acts of concealment are not the exception, but are, in fact, the norm.

The predicament of fistula has been depicted in the media and donor narrative as a twin crisis: abandonment in a time of need, combined with a spatial separation from kin and society through confinement, through setting apart. While the narrative of suffering highlighted by the fistula brand focuses largely on the external—that is, the treatment women are allegedly subjected to by others—most women’s narratives of suffering focus largely on the internal (as discussed in chapter ten). When women recounted their experiences, they talked about the shame they felt, their embarrassment, and the constant worry they endured wondering if they

would ever get better. And whereas the social pariah of the fistula story is defined by her spatial segregation just like a leper is assumed to be banished from home and village, women's experiences of separation are small acts of self-segregation and self-regulation.

When discussing incontinence of women in the Global North, the discourse is not one of outward mistreatment due to corrupted culture, but rather a conversation of shame and loss of identity managed through strategies of isolation and self-segregation (see Manderson 2011). The experience of women who suffer from incontinence in Western countries is focused on the ethos of the sufferer—her shame, her loss of identity, her feelings of betrayal by her own body—not the depravity of her social contacts. The same is not true of women with fistula in Niger, where the discourse tends to focus on forces external to the women—mistreatment from husbands and rejection from communities. However, I argue that the this focus on the external fails to capture the daily struggles of Nigerien women with fistula—the internal battles of identity, the emotional isolation, the anxiety of “passing” or fear of “outing,” the logistical complexities of quotidian concealment, and the relational repercussions of self-isolation and social distancing.

Most women did not live with oppressive and unrelenting mistreatment. Rather, women typically faced a few painful experiences that felt like a betrayal from those they trusted, select moments of humiliation. A sister that told her that she smelled. A husband who would not enter her room. These moments, while infrequent for most women, shaped their experiences of fistula and resulted in internal emotional struggles rather than external struggles. Incontinence affects women in the West and the Global South in similar ways, however, while Western women's stories paint a complex picture of shifting identities, shame, social norms, and psycho-social trauma, the metanarrative of fistula in the Global South focuses on outward mistreatment borne from the degeneracy of a society that does not consider “the lives of women worth saving”

(World Vision, n.d.). This neocolonial, globalizing, and reductionist perspective fails to give voice to women whose suffering reflects the mundane trauma of negotiating one's identity while constrained by an aberrant body.

Although most women relied on this two-pronged strategy of concealment and self-isolation, I found that if a woman with fistula was adept at maintaining her social links and duties to a large extent (visiting at funerals, weddings, baptisms, and so on), she was often able to sustain the respect of her social circle. Thus, despite the fact that most women with fistula felt apprehensive about attending social functions because these could bring them in especially close contact with people who might witness their leaking, it was precisely these acts of sociality that seemed to anchor them most effectively in the fabric of their communities.

Chapter 13

Conclusion

13.1 A Year Later

In the fall of 2014, several months after my departure from the field, I returned to Niger. During my brief visit in Niamey, I was able to speak to about two-dozen of the women I had come to know the year before, adding another time slice to their rich life histories.¹¹⁴

When I returned to Niamey, I found Fati, the first woman I presented in the introduction—the forty-two-year-old Tuareg woman who was healed of fistula seven years prior to her initial interview. I initially went to Fati’s father’s house, but was told that two months prior she married her fourth husband and had moved into his home. With directions from her stepmother and her new cellular phone number, I eventually found Fati’s new home. When I sat down to speak with her, Fati explained to me how her fistula had affected her three previous relationships:

I really thought that I would never get a husband again in this world... In my first marriage, my husband divorced me because of the urine. But my second husband, the father of Safi, it wasn’t because of the sickness. It’s he who brought me to CHU Lamordé for treatment... My third husband divorced me because of the urine. The third one, when he came to ask to marry me, I told him that I couldn’t because I still had the urine sickness, and he said he didn’t care about that. He insisted, and finally I accepted, but only about one, two, or three weeks later he said he couldn’t live with Safi and the urine. Safi is my daughter and it’s me who gave birth to her, so I couldn’t be separate from her until she grows up. He said, okay, take your stuff and leave my home.

Remarking upon gender asymmetries in Niger, Fati explained that, “It’s a woman who has patience because if she has to leave, she doesn’t know where to go, but a man, when it is a woman who has a problem, the man will throw her out, and replace her with another one.” She

¹¹⁴ Due to time constraints and concerns regarding Boko Haram (which had been more active over the Niger/Nigerian border), I did not return to Danja.

concluded that, “So if it is something that happens to the man, the woman has to be patient, especially when you have kids with him, and you will stay because of your kids, and see what God will do with him.”

After a few years living in the cramped, small hut of her father and his wife and children, tensions rose and money became tighter than ever. Because her mother was so poor and lived in a politically unstable region of a neighboring country, she felt she could not return to her mother’s home. So, for Fati, finding another husband was the only option. She explained to me how she met her fourth husband, Yusufu:

I didn’t know him, I didn’t know his family, and he, himself, I didn’t know him. And I was sitting there when he came and said, “I am looking for a marriage.” And I said, “You are looking for a marriage? So, you didn’t hear about me?” I said. And he said to me, “No.” And I said, “Me I have my own problem. Didn’t you hear about it?” And I said, “I have my own problem, so tomorrow if you marry me, you won’t say tomorrow that I hid something from you. You won’t say that I deceived you?” After that, I told him that I am still under treatment at CNRFO and Lamordé, and that Safi is my fourth birth, and if he wants a marriage, here is the situation. And he said, “Okay, I don’t mind. I am a poor man, so you must be patient with me. Sometimes I have, but sometimes I don’t. So if I have, we can eat, but if I don’t have, we must wait.” And I told him, “Ok, I am confident in you.” And so marriage was celebrated. I didn’t know anything about him and he didn’t know anything about me.

Hoping for a happy ending to Fati’s story, I asked Fati if she was pleased with her marriage with Yusufu, and she responded:

I’m still here. Life is going. But, I’m not feeling good. I’m really not feeling good. Sometimes we eat and sometimes we don’t. It’s been since yesterday evening that we ate; we didn’t have anything until now. I am not going to say I am happy in my marriage.

Seeing the disappointment in my face as I had longed for a better future for Fati, she shrugged—almost apologetically—and added, “Telling the truth is better than not.”

Fati’s husband walked into the room, and Fati’s jaw stiffened. She refused to make eye contact with him. She snapped at him, asking him for money. He said he had none and left the room, taking with him the last bowl of rice in the house. Fati had confided in me that her new

husband looked at her daughter with anger and impatience. Fati feared that Yusufu would hit the little girl, or decide that he did not want her in his home anymore.

Fati also explained that since the marriage, she had been experiencing gynecological pain. Although she initially suggested that perhaps something had gone wrong with her Cesarean section (a then four-year-old scar), the more we discussed it, the clearer it became that Fati suspected that her husband had given her a sexually transmitted infection—the diagnosis of which alone was far beyond her financial means, to say little of its treatment.

Speaking of her fistula, Fati had explained to me that, “before I got this sickness I was a poor woman, but when the sickness came, I became poorer.” For Fati, even having been healed of fistula for eight years, fistula continued to place constraints on her life—both financial and social. Fistula had reduced her fertility, increased the number of divorces behind her, and the number of years between her and a stable married life, which in her estimation drastically reduced her social value, leaving her with few marriage options—thus having to settle for Yusufu. The power fistula continued to exert over Fati—even after she was continent—was mediated by several converging factors: the absence of Fati’s mother in her daily life, which left her vulnerable; her lived poverty, which constrained her marital options; and gender inequality and having mothered children from men other than her husband, which decreased her power within her marriage. Indeed, even after her fistula was healed, and she was continent, Fati’s fistula continued to imprint itself on her body, on her marriage, and on her life.

I had returned to Niamey during the tail end of the rainy season. Because of the chronic nature of fistula, many women’s treatment seeking behaviors looks a lot like seasonal migration. In Niger, fistula centers’ numbers often swell during the dry season, when there is little work to be done in fields or with food preparation in villages, and peaking during the “hungry season,” or

the period between harvests when stored grains run out and there is little left to eat. Often during these periods fistula centers' in Niger were far over-burdened, with women with fistula sleeping two to a bed and shaded areas covered with sleeping mats. However, when I returned during the rainy season in the fall of 2014, very few women were at either CNRFO or Dimol, they were said to be at home helping in their families' fields. I was told that they would return after the rain.

Of the six women's dorm rooms at CNRFO, all of which had been in use for the majority of my fieldwork, one had been converted into storage and another was being used as an office for female personnel. Many of the beds were empty and the center's atmosphere was languid. The usual six or seven groupings of women (usually divided by ethnicity and then again by age) had been consolidated to three—the Hausa and Tuareg women spent their time on mats under a newly constructed tin-roofed hanger while the Zarma women congregated around the large tree in the central courtyard. The remaining women lounged on their beds in their rooms, spending time with their roommates or occasionally joining the two groups. Only a handful of women were left at Dimol.

In speaking with the women, I learned that since my departure, most had undergone between one and two additional surgeries. Some had returned home for a handful of months in between surgeries; some had not. Most claimed to be no better. In the year that had passed, little to no progress appeared to have been made in determining how to care for complex (and potentially incurable) cases. The women whose case files were scribbled with words such as “very difficult,” “no urethra,” “extensive scarring,” and “huge fistula” were disproportionately still at centers. Of the women at Niamey fistula centers who were noted for having the worst cases, the most complex fistulas, the most difficult to repair—those women were somewhat

unsurprisingly still at the centers when I returned a year later. These women still had not been told anything about their cases, nor given a timeline for their care. Disturbingly, when I asked several of these women how long they had been at the center, many of them told me the same length of time that they had told me the year before, as though time had ceased to advance.

Although of the women I spoke to, the vast majority of women were still incontinent, still waiting for answers, still searching for solutions—the small sample was certainly unrepresentative. The women who I did not speak with—those who were lost to follow-up, those who were no longer at the centers, who could not be reached by phone, those who had disappeared—those are often the women who have successfully attained continence and thus were able to resume their lives, severing connections with the fistula centers and infrequently returning for follow-up consultations. Sometimes these women find their way back to centers when they become ill (both with gynecological related complaints, but also bringing general health complaints to the center—a place they had come to rely on for basic health services beyond fistula care).

Of those women who left centers and did not return, most had left behind a contact number. Many women had cellular phones, and of those who did not, most were given one by a donor through reintegration funding. However, since the beginning of 2013, the Nigerian government had started to obligate Nigeriens to register their numbers with their cell phone companies using photo identification. Those with pre-existing numbers who did not go to one of the three major cellular phone carriers had their SIM cards and phone numbers cut. Because many rural people, particularly women, either have no form of identification, or are far from cell-phone headquarters' offices, many women lost their numbers. Thus numbers given at the beginning of the project were often no longer in service by the end of the project. Fewer than a

dozen of the women I tried to contact were reachable by phone. Each attempt I made to reach women was met with the same high-pitched, atonal French voice informing me that the number I was trying to reach was unavailable.



Figure 13.1: Photograph of billboard on the side of a main Niamey roadway advertising the government's campaign to register all mobile telephones. The text reads: "Republic of Niger, Cabinet of the Prime Minister, Telecommunications Regulatory Authority. If you have not already done so, identify yourself at your mobile operator before October 25th 2013. As of October 25th 2013, any unidentified number will be temporarily suspended before being permanently disabled November 25th 2013."

Still, through gossip, I heard of many of the women in my sample who were dry (or drier), who had returned home, who had remarried, or who had birthed children. During my time in Niamey, I witnessed the Cesarean section of a woman whose fistula had been successfully closed two years prior and who gave birth to her first living son. After five stillborn children, this child was her opportunity for a renewed future. Full of anxiety, she and I spoke before her birth, and we spoke after, hours after her successful Cesarean delivery as she joyously observed her small living son from the corner of her eye. Her husband had not made the trip down to see her birth, he had not sent money, and he had not called. But her mother waited anxiously outside her hospital room, reluctant to have left her daughter's side for the operation. Stroking her child's forehead, she ruminated on her future. "Everything has changed," she laughed. For this woman, her son represented so many transformations: the possibility of renewed warmth with

her husband, equality with her co-wife, and a new identity for herself—no longer a woman with the “sickness of urine”—but a mother.

I was also able to re-interview another young Zarma woman from my sample who might otherwise have been lost to follow-up. One Sunday during my time in Niamey, she was accompanied by four of her friends from the fistula center, moving her things from Dimol five blocks away to her new home. Two years before she arrived at Dimol with a fresh fistula, and there waited many months in vain for surgery, finally moving across the street to CNRFO where she eventually received her first operation, luckily attaining continence, and ultimately in the months that followed, meeting an honest, young man in the neighborhood and becoming his second wife. I interviewed her three days after her wedding. Her girlfriends were still packed into her small room—as it was customary for them to stay close to her for her first week of marriage in order to ease her transition into married life. Her hands and feet were covered in the deep browns and bright reds of ceremonial henna festooning the palms, toes, and fingers of all new Nigerien brides. She too had begun again.

Of the sixteen women in my sample who I was able to re-interview during my 2014 follow-up visit, twelve were still wet while only four were dry, and eleven were at either Dimol or CNRFO while only five were at home. During the previous year, three of the sixteen women I spoke with had undergone two additional failed surgeries each— all three women had undergone seven failed surgeries and were all three waiting at the center for their eighth operation. I was also surprised to see three women at the center, all of whom I had previously counted as dry. But, I learned that since I left Niger, their repairs had broken down and they had all begun to leak again. Yet, three other women had re-married in the capital, and two others had given birth to children. Of the 84 women with whom I did not speak, I cannot say how many had similar

stories of success and renewal to tell. But I suspect that for many women, life continued, and some were given an opportunity to start anew.

13.2 Fistula Work Within a Reimagined Development Landscape

In 1981, sociologist Margaret Murphy conducted some of the first social science research on women with fistula in the city of Zaria—a northern Nigerian city located about 200 miles south of my fourth field site, the Danja Fistula Center. Her findings highlight a dynamism of experience, in contrast to much contemporary writing on fistula:

The patient feels herself to be a social disgrace to the family. She is given food and shelter but frequently is segregated in the compound. She sleeps on her own, eats by herself, uses her own separate bowls and is not allowed to cook for others... The patient's mother remains kind and loving towards her but usually other women in the compound do not like her presence, smell and incontinence. The practice of Islam emphasizes cleanliness, especially with regard to sexual intercourse, so any affected women is considered unclean and is no longer allowed to pray, though in time her condition may come to be regarded as incurable and she will be allowed to pray again. Patients themselves expect to be treated as outcasts; for example, at social gatherings they expect to be kept away from the assembly lest they cause offence. (Murphy 1981:147-148)

Nearly 25 years before I conducted my research, nearly that many years before fistula was well known to a Western audience (and thus before the construction of the media and donor narrative), fistula was presented with nuance. Fistula was shown to affect women's lives in complex ways—primarily resulting in internalized shame and expressions of self-segregation. The way it impacted women was known to have its own life course, first experienced as acute and thus limiting in specific ways, and then chronic (and often incurable), and managed. A woman with fistula was not banished from the home, as often portrayed in contemporary donor and media literature, but she often no longer shared beds or meals. And while other women “did not like her presence, smell and incontinence,” she was loved fiercely by her mother—not a social pariah, abandoned by all.

Twenty-five years later, situated within an international health landscape defined by neoliberal reforms that result in philanthropic approaches to humanitarian intervention, obstetric fistula—and the women who suffer from it—has been marketed as “a nightmare for African women” (LaFraniere 2005). Stripped of the nuance exhibited in Murphy’s writing of women with fistula in Zaria, or the complexity of their experiences, fistula is said to stigmatize all women it touches, degrading their social networks, debasing their senses of selves, corroding their marriages, and destroying their economic and emotional stabilities. Yet, as demonstrated by voices of the one hundred women with fistula in Niger that I came to know, the lived realities of fistula and women’s personal strategies for living self-management are far more complex and sophisticated. They are rich and varied—defined by daily struggles, internal shame, and social betrayals, just as they are defined by networks of caretaking, stability, secret-keeping, love, and bonds reinforced (rather than degraded) by illness.

In relation to fistula-work, a rather widely-cited quote by Foucault (2003[1983]) aptly summarizes this dissertation’s stance on fistula interventions: “My point is not that everything is bad, but that everything is dangerous, which is not exactly the same as bad. If everything is dangerous, then we always have something to do. So my position leads not to apathy but to a hyper- and pessimistic activism” (104). The discourse surrounding fistula can be dangerous—having but conceptual and concrete implications on how we think about intervening into Africa generally and fistula specifically—but I am not suggesting that this danger should not lead us to reject fistula interventions nor to oversimplify the ethics involved. Instead, I posit that we should become more attentive to the complexity and cautious with our conclusions. We must be ever more attentive to the ethics surrounding the provision of fistula care, and transform knowledge gained from ethnographic endeavors into more insightful, targeted interventions.

In an exploration of anthropology's relationship to humanitarianism, Didier Fassin (2010) explores why the world of humanitarianism tends to elude critical analysis. He argues that anthropologists are far more comfortable criticizing (and others are far more receptive to criticisms of) "the third figure," or, "the money-grubbing boss, the insensitive bureaucrat, the cruel soldier" rather than the "victims of poverty, illness or oppression and the benefactors who assist, protect, and struggle to defend them" (37). The "untouchability" of certain actors and values associated with humanitarian intervention may be due—at least in part—to the historical-religious overtones of the sacredness of charity. As such, demonstrating that recipients of aid strategically deploy tactics to obtain what they want or that purveyors of said aid may be cynical, indifferent, cruel, or simply wrong upsets a "compassion consensus" wherein "the ill fortune or distress of some and the solicitude of others are understood to harmoniously respond to each other" (36).

Criticism of these actors or institutions is often met with some hostility, yet Fassin argues that "criticism is both loyalty and displacement" and that "the accuracy of an analysis can be measured by the discomfort it causes in both the person who produces it and the person who receives it" (43). Fassin suggests that anthropologists adopt a position of "liminal critique" or "distanced interiority" whereby the form of truth telling produced may incur a high cost for the teller (an idea originally called parrhesia by Foucault [1983]). Fassin argues that anthropological critiques of humanitarianism can provoke a sort of "anthropological aporia," or "questions that touch on the very foundations of humanitarian action and admit of no solution given the state of the contemporary world" (50). Ultimately, Fassin argues that this form of truth telling exposes the teller to "virulent reactions from actors who feel they possess a legitimate truth and whose

authority—together with the authority of whatever the represent—may be shaken by such revelations” (51).

This research may be considered controversial to some readers, provoking an “anthropological aporia,” as these findings might be considered threatening to the fistula industry. If fistula does not universally transform all women into pariahs, hermits, and outcasts, then some readers might question the merit of any intervention at all. If these women are not “superlative sufferers,” does their suffering merit attention? Or more pragmatically, could money be better spent elsewhere? Does intervening do more harm than good? For other readers (less willing to abandon wholesale the importance of intervention into fistula), the question might become one of allocation of resources. For example, if surgical outcomes are poorer than commonly cited, should fistula prevention be prioritized over fistula treatment? Or, should fistula prevention focus on community awareness building when research demonstrates that the quality of available health care is so low, or should resources instead be invested in improving emergency obstetric care at the local level? Is it ethical to send women home with sewing machines, large sums of money, or invest significant resources into courses (that may benefit women but will probably prove far less transformative than imagined) when basic maternal care is so poor? Should fistula care be rationed? If so, how many repeat surgeries should be attempted on women to restore continence when long backlogs of women wait at centers for first-time surgeries? But these questions need not be threatening to those involved in fistula work. Rather, ethnographic knowledge of people, places, and contexts offers some insight into these difficult (and deeply contested) issues.

Born from a “hyper- and pessimistic activism” (Foucault 2003[1983]:104), I attempt to reimagine how fistula programming might be improved. Although anthropologists are trained to

critique—artfully problematizing and relentlessly scrutinizing—we often stop short of offering solutions. It is not our forte. Still, translating women’s lived experiences into research, and then research into action, change, and reform, is essential. Below, I offer few ideas on how to constructively move forward.

Most fistula interventions endorse a three-pronged approach, focusing on prevention, treatment, and reintegration. I suggest how women’s experiences offer insight into all three levels of intervention. Although these suggestions are specific to fistula care in Niger, many may be relevant when thinking about fistula care in other parts of the Global South.

The knowledge gained from this research can improve prevention activities in myriad ways, such as: improving referral systems during problematic labors and incentivizing quick referrals, and ensuring vertical rather than horizontal referrals; increasing the quality of services women receive at health centers (with particular focus on enriching the quality of training low-level healthcare practitioners and increasing expertise on C-Sections through more and better trainings); lobbying government agencies for increased accountability of practitioners and health centers for medical malpractice; and addressing biomedical mistrust through improved clinical communication (for example, explaining to a woman what kind of fistula she has and exactly how she developed it in an effort to decrease perceptions of iatrogenic fistula). All of these prevention activities generally intervene into healthcare systems that are currently failing (largely rural) women.

Because this research was primarily sited at fistula center, it is unsurprising that the majority of suggestions for improvement of programming relate to fistula treatment at centers in Niger. They include: the development of referral mechanisms and surgical expertise, the radical reduction of long waits at centers, and improved clinical communication. It is too common that

women take months (or years) between the development of their fistulas and their entry into an appropriate fistula care center due to poor clinician-patient communication and the lack of coordinated responses in health centers all along the referral chain. To address this, clinicians and administrators at all health centers in Niger must be better informed regarding basic detection and diagnosis of fistula, the existence of fistula care centers, current contact numbers, and dates for surgical missions. Rapid referrals would get women to appropriate centers more quickly, reducing the financial, social, and emotional burdens for women and their families of living with untreated fistula.

Coordinated efforts should be made in order to increase surgical expertise and local capacity through surgical trainings. Additionally, in what I consider the most important of all interventions, long wait times must be addressed. It is imperative that the time women wait for surgeries at centers be dramatically decreased. To do this, fistula care in Niger must rely less on foreign missions for surgical interventions, and could strengthen collaboration rather than compete, in order to pool resources. Also, women with fistula must not be considered a source of revenue for fistula centers—acting as “employees” of sorts who fill beds and thus provide income for the centers from large multinational agencies who pay their room and board. This funding scheme may in fact act as a disincentive to actually operate on women. If surgeries cannot be provided within one month, in an attempt to minimize the time women spend at center and maximizing time spent at home (and thus minimize the social consequences women incur due to their absences from home), rather than waiting at the centers for indeterminate periods of time, women should be given a date to return to the center for surgery. Women who opt to wait at centers could continue to stay, but this scheme would allow women who chose to maintain their social relationships at home the opportunity to do so.

Additionally, clinical communication between clinicians and women with fistula can be improved. Many women come away not understanding why they got fistula, and often are not told that they have fistula until they arrive at a fistula hospital. Women are worried about future fertility, and many do not understand the relationship between other morbidities developed during labor (such as foot drop, or the removal of their uterus due to uterine rupture). Fistula centers could organize counseling sessions during which time the etiology of women's injuries are explained, as are potential options for closure—including contingency plans if surgeries do not work—and options for managing chronic fistula are discussed. Centers could give women more realistic expectations regarding surgical outcomes so that women can make more informed decisions regarding when to stop pursuing surgical treatment.

Indeed, modest surgical success rates should continue being addressed. There should be an increased scrutiny of data, as well as heightened surgical oversight. In centers, women should be taught how to live with and manage fistula, changing the discourse from fistula as an acute problem to fistula as a potentially chronic condition. Also, the organization of a surgical committee to evaluate “incurable” cases must be prioritized (currently, women who have complicated fistula are often not operated on but rather stay at centers for years). Women with the most difficult cases must not continue to linger at fistula centers across Niger unaddressed, told to wait, that they will be operated on—this represents a gross violation of these women's dignity and rights. While these women wait at fistula centers for improbable surgeries, their social lives degrade as the years go by. Their husbands move on and remarry; their friends build social networks that do not include them. Soon, they have little social space to return to. While the global fistula narrative highlights the social consequences of fistula, for women whose difficult cases have resulted in prolonged absences at home—moving from one center to the

next, or waiting on hospital grounds, hoping to be called for surgery—it is often the care-seeking itself that degrades their social lives, not their fistulas. This must be recognized and addressed. Women who cannot or will not receive timely care must not be kept at centers where they nurse hopes of cure while their social lives at home slowly degrade. For women who have no supportive networks to return to, alternate solutions must be envisioned and enacted.

Finally, women’s experiences also inform the ways in which reinsertion intervention could be reimagined in order to better meet women’s needs. Regarding reinsertion, interventions should be crafted to respect women’s privacy, allow women to opt-out of programming, and should integrate maternal health modules. Additionally, the overall quality and structure of reinsertion programming must be improved. Indeed, reinsertion interventions must acknowledge that women conceal their fistulas and respect women’s choice to “pass” by allowing for more secrecy by not calling husbands or family members and by opting not to accompany women home. For some women, the most effective way to reduce fistula-stigma is to reduce the time they spend away from their homes in the pursuit of treatment, and for this reason, reinsertion courses should not be compulsory or even pressured. It must be addressed that many women are denied their papers and stopped from leaving centers when they wish, often forced to wait months after their initial requests to leave before they are released. Due to the high rates of stillborns among women with fistula, women should be trained on how to avoid infection and recognize and act upon signs of problems early in pregnancies.

* * *

How can we tell stories of suffering that neither exploit the sufferers nor trivialize their trials? I argue that ethnography is an answer. Neither reductionism nor obfuscation, ethnography’s only goal is to capture women’s words and actions, to translate, and to place them

in context. In listening to women with fistula in Niger, I have heard stories of incredible strength and determination in the face of hardship. Through decades of fistula concealment or dogged quests for treatment, women demonstrate agency despite myriad constraints. Women's fistula narratives so often expose vulnerability and shame, deep senses of loss for stillborn children, broken marriages, and shattered womanhood. Yet, still there is hope—a fiercely loving mother, a new boyfriend who does not care about a woman's incontinence, a community that displays no mistreatment towards a woman with fistula. Women with fistula have a voice (or rather, many voices), we just need to listen.

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Appendix A

Date Name Location Occupation Sex Fistula/ non fistula Age		1	2	3	4	5	6	7	8	9	Total
		Do people avoid them?	Do people refuse to eat with them?	Do people refuse to talk with them?	Do people refuse to shake their hands or touch them?	Do people gossip about them?	Do people fear catching this?	Do people avoid their children?	Do people feel disgust for them?	Do people avoid marrying them?	
A	Leprosy										
B	HIV/AIDS										
C	Tuberculosis										
D	Epilepsy										
E	Mental Illness										
F	Fistula										
G	Prostitution										
H	Polio										
I	Venereal Disease										
J	Women whose children have all died										

A positive response for each question is marked with one point. A-J each have 9 possible points.

Appendix B

Because of your fistula, how often have the following things happened to you?	Never	Once or twice	Sometimes	Always
EXTERNAL STIGMA				
1. People have refused to share food with you from the same plate				
2. People have refused to drink from the same cup as you				
3. People have mocked or insulted you				
4. People have commented on your odor, or asked you to leave because of it				
5. You have lost friends because of your fistula				
6. People have told you that your life is over, or that you have no future				
7. People have told you that God is punishing you, or that your fistula is your fault				
8. People avoid you.				
9. People believe that your fistula is contagious				
TOTAL				
INTERNAL STIGMA				
10. You have felt ashamed because of your fistula				
11. You have felt useless because of your fistula				
12. You have felt like a burden to your family				
13. You feared that others will gossip about you				
14. You feared that others would look at your skirt, your feet, or where you were sitting to see if you are wet.				
15. You were ashamed that you could not go to public meetings, weddings, or baptisms				
16. You feared that others would find out that you have fistula				
17. Because of your fistula, you did not leave your house.				
18. Because of your fistula, you felt like you were no longer a woman				
TOTAL				

“Never” is scored as zero points, “once or twice” as one point, “several times” as two points, and “most of the time” as three points.

Appendix C

Because of your fistula, how often have the following things happened to you?	Never	Once or twice	Sometimes	Always
ENACTED STIGMA				
1. People have refused to share food with you from the same plate				
2. People have refused to drink from the same cup as you				
3. People have mocked or insulted you				
4. People have commented on your odor, or asked you to leave because of it				
5. You have lost friends because of your fistula				
6. People have told you that your life is over, or that you have no future				
7. People have told you that God is punishing you, or that your fistula is your fault				
8. People avoid you.				
9. People believe that your fistula is contagious				
TOTAL				
TREATMENT FROM HUSBAND				
1. Your husband has divorced you because of your fistula				
2. Your husband has taken a new wife because of your fistula				
3. If you don't get better soon, you fear that your husband will leave you				
4. Your husband has stopped supporting you financially or emotionally				
5. You have not seen your husband since you got fistula				
6. Your husband's family, or his friends have pressured him to divorce you				
7. Since you've gotten fistula, you have not had sex with your husband				
8. Your co-wife has mistreated or insulted you because of your fistula				
9. You do not want to return to your husband after you are healed				
TOTAL				
FELT STIGMA				
1. You have felt ashamed because of your fistula				
2. You have felt useless because of your fistula				
3. You have felt like a burden to your family				
4. You feared that others will gossip about you				
5. You feared that others would look at your skirt, your feet, or where you were sitting to see if you are wet.				
6. You were ashamed that you could not go to public meetings, weddings, or baptisms				
7. You feared that others would find out that you have fistula				
8. Because of your fistula, you did not leave your house.				
9. Because of your fistula, you felt like you were no longer a woman				
TOTAL				

“Never” is scored as zero points, “once or twice” as one point, “several times” as two points, and “most of the time” as three points.