

Transforming Obstetric Fistula through Concealment in Niger

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Obstetric fistula, a birthing injury caused by obstructed labor and that results in chronic incontinence, is frequently described by donor and media narratives as an eminently visible condition resulting in social stigma. However, through ethnographic research in four fistula centers in rural and urban Niger, this research revealed that the majority of the 100 women interviewed hid their conditions from their communities, kin, and even husbands. Women invested their time, energy, and finances into these strategic acts of concealment. Yet, concealment came at a high price to women's psychosocial health as the women who were most successful in "passing" as whole and healthy were often seen by their kin and communities to have rejected vital tenets of relational reciprocity. Additionally, it was often fistula centers that unintentionally undermined women's concealment efforts, outing them within their communities. This research demonstrates the importance of ethnographic insight in reshaping fistula interventions to better serve women.

Key words: obstetric fistula, Niger, stigma, concealment, coping

Seven years before I came to know her, then twenty-year-old Satima was carried in her brother's arms into the small emergency and triage room at the *Maternité Issaka Gabozy*, Niger's top maternity hospital. Satima's labor had begun six days prior in her rural village, located far from quality emergency obstetric care. Unlike her two previous deliveries, Satima's labor had not progressed normally. By the time she was wheeled into the operation block for an emergency cesarean section, her body had sustained permanent damage. That afternoon was one of profound loss for Satima—she had lost a dangerous amount of blood, lost consciousness, lost her child, and ultimately, she also lost her continence.

One in twenty-three Nigérien women will die from maternal causes in their lifetimes, and for every woman who dies from obstetric complications in Niger approximately ten more suffer from acute maternal morbidity (World Bank 2018; Prual et al. 1998). Although Satima survived her traumatic labor, when she regained consciousness, she found herself in a pool of her own bodily waste. Five days after she delivered her stillborn son, the protracted pressure of the fetal head against the soft tissues of her pelvic wall had resulted in an

abnormal anatomical pathway; an unremitting stream of urine began to flow from her vagina. Satima had developed what is referred to in Hausa (Niger's largest ethnic group) as *ciwon yoyo fitsare*, the sickness of leaking urine.

By the time I came to know her, Satima had spent seven years pursuing surgical treatment for her condition, moving tirelessly between local healers and biomedical centers and across national borders in a quest for social and corporeal "normalcy." She estimated that she had spent a total of four years living on fistula center grounds, waiting for repair surgeries intended to close the hole and restore her continence. When we met, Satima had already undergone five failed surgeries.

Ultimately, biomedicine failed to heal her leaky body. Yet, these centers were sites of transformation nonetheless. It was at her initial stay at a fistula center that Satima first learned how to present as a woman who was well, even if the stitches that would not hold and the tissues that would not mend meant that she could not truly embody one. Like many other women with fistula, it was at the fistula center that Satima learned how to conceal her incontinence, her condition, and her repeated surgical failures; she learned how to *pass* as a woman who was whole, healed, and healthy.

In this paper, I consider the specific sacrifices women make in their quest for social (if not corporeal) normalcy in the poor, polygynous, and patriarchal setting of rural Niger. I explore the two-pronged strategy of disguising symptoms and self-isolating that women with fistula adopt, the social dynamics that enable or constrain concealment, the high social cost of "passing," and how fistula centers pose threats to women's identities as whole and healthy. Ultimately, I offer

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suggestions as to how ethnographic insight can lead to more ethical and efficacious interventions.

The Sickness of Leaking Urine

Caused by prolonged and obstructed labor unrelieved by biomedical intervention such as cesarean section or forceps delivery, an estimated one to two million women—primarily in sub-Saharan Africa—live with persistent incontinence of urine and/or feces through the vagina due to the relatively unknown birthing injury (Adler et al. 2013). Leaving women to leak, smell, and often compromising their reproductive futures, obstetric fistula is thought to result in profound social rupture. In much of the related popular media, donor, and academic literature on fistula, the condition is causally linked to social marginalization, abandonment by kin, divorce, spatial segregation, community exile, as well as myriad psychological repercussions such as depression and suicidal ideation (see, e.g., Brugière 2012; Hamlin 2001). Humanitarian and media narratives present women with fistula as “the world’s modern-day lepers,” and victims of “a fate worse than death” (Kristof 2016; Winsor 2013). It is through biomedicine and surgery’s “silver bullet” that women are thought to achieve physical—as well as social and emotional—redemption (see Heller and Hannig 2017 for analysis of the fistula narrative).

My research complicates these dominant narratives of social stigma, exposure, abandonment, isolation, and corporeal transformation. Although obstetric fistula is often portrayed in the donor and media literature as an eminently visible marker of a woman’s identity, the majority of women I came to know in Niger had made significant efforts to maintain control over the information others had about their conditions. I found that women with fistula invested 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 existed in the internal shifts in identity of the women with fistula themselves. While the weight of secret-keeping and the emotional and material costs of concealment work affected women’s psychosocial health, these women were able to avoid the most pernicious social consequences of the condition.

These efforts to conceal not only fistula’s symptoms but transform one’s public identity from someone who is “broken” to someone who is “normal” or “well,” surpassed notions of “coping” common in research on chronic illness management, where afflicted individuals attempt to mediate the negative externalities of their conditions (Bilgic et al. 2015; Pereira, Pedras, and Senra 2018). Concealment efforts—women’s refusal to disclose—were transformative, allowing women to at least publicly embody whole (non-fistulous) and healthy (“normal”) identities. Women who concealed avoided the types of social marginalization and community mistreatment commonly linked to fistula. No one commented on their smell; no one refused to share meals; no one exiled them to the outskirts of the community because no one (or few) even knew of their conditions.

Yet, for women in Niger, concealment was not an unmitigated benefit, as the illusion of normalcy came at a cost. The women who were most successful in disguising their conditions often suffered the consequences of perceived social deviance, as they failed to meet attendant social obligations. They were seen by their kin and communities to have rejected vital tenets of relational reciprocity. While myriad relational, emotional, and financial repercussions are directly attributed to fistula stigma in media and humanitarian narratives, I offer an alternate explanation. I contend that when women did experience an attenuation of social ties, a loss of social status within their communities, increased poverty, decreased emotional health, the dissolution of their marriages, or other social consequences frequently connected to fistula, the cause may instead be, at least in part, the result of women’s concealment strategies: their volitional non-participation in expected and obligatory social rituals and relationships.

Additionally, borne from a misperception of the social lives to which women with fistula are set to return, fistula centers repeatedly, though unintentionally, undermined women’s efforts to conceal. Through donors’ gifts of fabrics adorned with fistula-related logos and campaigns, televised donation ceremonies, and accompaniment back home by clinic staff following the completion of reintegration programs, women’s confidentiality was repeatedly breached. Women’s efforts at concealment and self-management were continually jeopardized by various stakeholders who mistakenly assumed that fistula had rendered all women social pariahs. As non-profit organizations and government health systems move forward to address the fistula crisis, the ethics of concealment and confidentiality must be better understood and incorporated into interventions.

Methods

Over the course of one year (2013) and two summers (2010 and 2014), I conducted mixed-methods research in four fistula centers in urban and rural Niger with 100 women with fistula from six ethnic groups, predominantly Hausa and Zarma (see Table 1 for demographics of sample). I also spent time with and interviewed nine family members of women, five husbands, and twenty-three fistula experts. 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). To do this, I triangulated, using in-depth interviews, participant observation, and structured surveys. All interviews were conducted in Hausa or French (both of which I speak) or Zarma (which I do not speak; I relied on my female research assistants for translation).

Two of the four centers where I based this research were state-run (*l’Hôpital National de Lamordé* [Lamordé] and *Centre National de Référence des Fistules Obstétricales* [CNRFO]), and two were privately managed by NGOs

Table 1. Demographic Characteristics of 100 Women with Fistula

| Characteristic | <i>n</i> (%) | Average |
|--|--------------|--------------|
| No. of women | 100 (100) | |
| Age at time of interview | | 31.0 (±10.6) |
| 15-20 years | 16 (16.0) | |
| 21-35 years | 57 (57.0) | |
| 36-70 years | 27 (27.0) | |
| Years living with fistula | | 6.7 (±8.6) |
| <1 year | 19 (19.0) | |
| 1-4 years | 35 (35.0) | |
| >4 years | 39 (39.0) | |
| Number of total pregnancies | | 3.7 (±2.9) |
| 0-1 | 36 (36.0) | |
| 2-6 | 44 (44.0) | |
| 7+ | 20 (20.0) | |
| Number of previous repair surgeries | | 2.8 (±2.2) |
| 0-1 | 39 (39.0) | |
| 2-4 | 41 (41.0) | |
| 5+ | 20 (20.0) | |
| Months waiting at clinic at initial interview* | | 5.8 (±9.9) |
| 0-2 months | 30 (38.5) | |
| 3-9 months | 36 (46.2) | |
| >9 months | 12 (15.4) | |
| Marital status at initial interview | | |
| Married | 38 (38.0) | |
| Divorced | 23 (23.0) | |
| Separated | 36 (36.0) | |

* Only the women who were looking for surgery were counted (n=84); eight women could not estimate how long they had been at the center, so their data was left out of calculations.

(Dimol and the Danja Fistula Center). Lamordé, CNRFO, and Dimol were located in Niger's capital, Niamey, while Danja was approximately 700 km east of the capital, 30 km north of the Nigerian border. Only Danja reliably offered surgeries; at Lamordé and CNRFO surgeries were irregularly performed and required long waits; and although Dimol occasionally offered courses and trainings, the center offered no surgical possibilities (unbeknownst to the women waiting). Evidently, the quality and timeliness of care offered to women at these centers varied tremendously. Yet, all the centers afforded women who were far from home a valuable opportunity: time away from their communities where they could restore their general health and refashion their identities through exposure to novel techniques and technologies.

Working to "Pass"

Concepts of social stigmas 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, stigma can be separated into enacted or external stigma (actual experiences of discrimination) and perceived or internal stigma (shame and internalization of stereotypes).

Goffman (1963:42) situated "passing" as "the management of undisclosed discrediting information about self." In order to manage, mitigate, or resist social stigma, one "presents himself as what one is not" (Rohy 1996:219). The concept of "passing" is used in the contexts of race, ethnicity, gender, sexuality, religion, or disability to highlight the fluidity of social boundaries—the desire (and capacity) of individuals in marked social categories to be selectively "misread." Passing is performative, a cultivation of self through routinized everyday acts. Those who engage in passing work know that it is illusory. This selective revelation (and obscurity) leads to a persistent fear of discovery.

Women with fistula often explicitly tried to "pass" as whole (non-fistulous) and sometimes even altogether healthy (generally "well" or "normal.") They employed strict forms of self-management to hide any incriminating evidence of leaks, smells, or other indications of incontinence from neighbors, friends, and some kin. For some women whose conditions had been previously acknowledged within their communities, this meant concealing surgical failure and thus passing

as “healed.” Others who were able to conceal from the onset of their conditions went a step further, not only concealing the specific nature and effects of their conditions but also hiding that they were ever sick at all. A surprising number of women with whom I spoke explained how through ingenuity and discipline, they had been able to elude the suspicions of their communities, friends, families, co-wives, and—most impressively—husbands.

Seventy-four percent of the 100 women I came to know had attempted to conceal evidence of their incontinence and manage the information about their condition; many of whom were quite successful in their efforts. Fifty-five women hid their conditions from all or most of their social contacts. For thirty-six women, only their immediate family or closest contacts knew about their incontinence and its cause. Incredibly, fifteen women were able to successfully conceal their fistulas from even their husbands, eleven women claiming that he was still unaware of her condition at the time we initially spoke.

Yet, as ubiquitous as concealment work is in the lives of women with fistula, and as consequential as it proves to be, the concealment work of women is largely overlooked in the extant corpus of fistula literature.² Even the literature that does recognize women’s investment in self-regulation generally focuses on *coping strategies* rather than concealment. In line with my findings on women’s techniques to self-regulate, these studies found women with fistula in sub-Saharan Africa to regularly deploy some or all coping strategies, including: the utilization of pads, diapers, and dark clothing; strict regimes of hygiene; extra or special clothing to hide leaks; the limitation of water intake; the use of perfumes and scented lotions; abstinence from sexual activity; and social isolation (see Kabayambi et al. 2014; Okoye et al. 2014). Yet, these few studies too often dismiss women’s efforts as “inadequate” and “non-effective social measures” (Kabayambi et al. 2014:359).

While some women I came to know did seem to *cope* more than *conceal*, attempting only to manage their leaking and its accompanying smell, a stunning number of women’s efforts far exceeded this. Their efforts were not just regulatory, they were transformational. While concealing often involves coping strategies, the focus on coping overlooks women’s intention to not just reduce the severity or visibility of leaks but to be misread. Through daily self-management practices, women enacted a refusal to disclose, intentionally reshaping their visible identities as both whole and healthy.

To pass, women with fistula engaged in dual strategies of concealment: (1) quotidian changes in behavior, dress, and hygiene in order to disguise incontinence, and (2) systemic relational changes, whereby women modified the ways in which they engaged with their families, friends, husbands, households, and communities. Women’s days were often dominated by their efforts to conceal as they carefully tended to fabric pads, diligently bathed, selectively fasted, tightly controlled circulating information, and heavily relied on perfumes to cover odors.

Although women with fistula have conceived of many innovative management solutions to incontinence, the most

ubiquitous strategy—used by nearly all women I came to know—was the utilization of fabric pads. Yet, most women lacked experience managing constant vaginal flows, historically experiencing light menstruation or elongated periods of amenorrhea (due to pregnancies, lactation, and sometimes malnutrition), and thus had little existing knowledge about the use of pads at the onset of their fistulas. Fabric pad construction, utilization, and hygiene was taught and learned among women in centers, sometimes through direct teaching by clinic staff, but most often informally, through junior women’s observation of more experienced women’s daily management routines while women lived and bathed in close quarters. In places with limited resources, women innovated solutions, creating their own appropriate technologies for incontinence management and concealment. Women used rags, towels, and foam stripped from couch upholstery to make pads, and plastic sheeting or crocheted plastic bags to sleep or sit on or to make water-resistant protective garments, depending on the severity of their incontinence.

To safeguard against leaks, many women also dressed to conceal their wetness, wearing skirt wrappers, which customarily end at the ankles, extra-long so that they cover feet. Some women switched from the more popular chest-length *hijabi* to a more conservative floor-length veil, thus concealing any stream of urine that might be visible on their skin. Others wore double or triple layers and darker material.

Women also engaged in a spectrum of self-isolation behaviors in order to limit their risk of leaking publicly (and thus “outing” themselves). Women felt most comfortable when they were able to socially and physically distance themselves from community members and sometimes even kin. They left their homes less often, opted out of social commitments and reciprocal relationships, accepted marital separations to avoid close proximity to co-wives, and even relocated, moving from rural villages to larger urban towns or cities where they enjoyed relative anonymity. As they explained, staying home and self-isolating provided them some distance from the anxiety, shame, and humiliation they might experience if others saw their bodies out of control. I found that rather than being subject to overt discrimination, exile, and distancing by their communities as frequently suggested in donor and media narratives, most women with fistula retreated from society of their own accord.

The Presumption of Cure

Some women admitted that at the onset of their fistula, concealment was difficult, if not impossible. “Fistula was not an illness I could hide,” Hadiza (age 37, Fulani) explained. “Everyone who had ears knew I had it,” Raha (55, Hausa) averred. For women like Hadiza and Raha, it wasn’t until after their first departure from their villages for fistula treatment centers that they learned techniques for passing.

Because obstetric fistula is most often the result of a near-fatal obstetric catastrophe, directly following a delivery, women frequently experience injuries that may

be more painful, worrisome, or urgent than fistula. Along with mourning a stillborn child, women may be unable to walk, may experience bleeding or infection, and may experience intense pain. As Aissata (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.” This period directly following the onset of fistula, when women are most ill, is a particularly vulnerable time for exposure because, generally, the management and concealment of incontinence is impossible and frequently deprioritized by women and their families.

Due to visitation customs in Niger, where it is typical for neighbors, extended family, and community members to come to the home of the ill to pray and offer well-wishes, it is when women are least capable of self-regulating or concealing their incontinence 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 (and because these community members have less allegiance to the woman, they are most likely to spread the news within the community). Many women reflected on this period with some resentment, recalling visitors who they suspected came not out of compassion but curiosity. Nafissa (30, Songhai) explained: “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 was only after women regained their strength that they became 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. Rather than a physical transformation, it is often an illusory refashioning of the exterior. In fact, I found the rates of surgical success—defined here as both fistula closure and restored continence—to be quite low; only 36 percent of women in my sample who underwent repair surgeries attained continence at the end of the research period, in contrast to popular donor and media narratives which frequently claim 90 percent cure rates (see Heller 2017 for more on surgical outcomes). However, because rural communities exposed to radio messaging about fistula (which positions fistula as a quick and easy surgical fix) were often unaware of possible, or even probable, poor outcomes of fistula surgeries, women were able to profit from community assumptions of biomedical potency. Therefore, when a woman returns home, community members may remark upon the visual cues of cure—dryness, re-established strength, perhaps an increased confidence, new clothing, and often weight gain. Some women either opted not to correct others’ assumptions regarding the restoration of their continence, indirectly validating assumptions about their repaired bodies, or were active in furthering such assumptions, explicitly claiming to be cured.

For example, following the development of her fistula when she was eighteen years old, Tshara (40, Hausa) continued

to live peacefully with her co-wives and husband (birthing eight more children, four of whom survived). With the exception of her mother, Tshara had 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.” She explained that because most people in her village were too polite to ask her directly about such an intimate part of her body, she was not often in a position where she had 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, “*Lahiya lau!*” (I have health!) Then it is done.

Admitting that her deception was sometimes more direct than indirect, Tshara laughed, “As for my husband, when he asks, I just tell him that I’m healed. ‘*Alhamdulillah*’ (Praise God) I say.”

Concealment Capacities and Household Dynamics

Not all women’s conditions, however, lent themselves equally to being concealed. A woman’s ability to conceal her fistula depended on various factors including the severity of the condition, the type of fistula, local customs following the onset of fistula, household spatial configurations, the number of co-wives, and a husband’s nightly rotation patterns among his wives. For example, a woman with a large fistula or extensive damage leading to severe leakages may have more difficulty concealing her incontinence, while a woman with a smaller fistula or residual stress incontinence was often capable of concealing her condition for extended periods of time. Not all fistulas are the same, and over time, due to pregnancies, childbirths, or surgeries, they may improve or worsen, affecting one’s ability to conceal. Additionally, the spatial configuration of one’s home can be an important factor mediating concealment capacity. A woman with no private space may find it difficult to secretly wash and dry her cloth pads, while a personal shower facilitates such concealment work.

Fatouma (32, Tuareg) hid her incontinence and any indication that she was unwell from even her husband for seven years. But with her eighth pregnancy, her fistula worsened and became more difficult to conceal. 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, I don't drink *fura* [sour milk and millet] or water. I limit what I take in. Then it doesn't run much. Before my eighth birth, my condition wasn't so bad—it was easy to hide. But with the birth, it has gotten much worse and harder to hide....

Fatouma could hide her fistula for seven years because it was not very severe—she did not leak persistently or noticeably. This might explain why she avoided returning to the hospital—operations are an economically and socially costly pursuit, which can take a woman away from her home for many months and thus threaten her identity back home as a well person. Operations also jeopardize women's social positions within their households, as co-wives often compete for scarce household resources. But, with the birth of her baby, Fatouma's fistula became worse, and the cost/benefit analysis of care seeking changed: continuing to conceal her fistula became too costly.

In a country defined by perpetual scarcity, co-wives (and their children) are in constant competition for scarce household resources and their husbands' affection. Unsurprisingly, in the context of illness, co-wives can prove harmful to women. Co-wives may use a woman's injury to gain power over her within the household, damage her status within her community, alter her relationship with their husband, and jeopardize her concealment efforts through gossip and outing. Yet, in spite of the difficulties involved in sharing a spouse, co-wives can, at least temporarily, support women's concealment work, buying time for women to care for their bodies while husbands invest in a second relationship and family.

For example, Fatouma 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 (their husband ate and slept with each wife for two consecutive nights), which allowed her to eat and drink normally when her husband was with her co-wives, followed by two fasting days (intended to limit leakage) during her rotation with her husband. If she had no co-wives, or even if she had only one, her ability to fast continually or with fewer breaks would have been difficult, if not impossible, posing threats to her health. Often, it was women without co-wives who came to fistula centers with painful bladder stones due to chronic dehydration (which delayed surgical treatment; see below). This is only one example of how the high prevalence of polygyny in Niger dramatically affects the lived reality of the condition and its concealment. Women who concealed their fistulas from those closest to them, particularly their husbands, frequently mentioned the importance of their co-wives in maintaining sufficient free time and space to refine their "passing" strategies.

The Price of Passing

The physical, emotional, and social consequences of concealment work can be severe. Not only does strict vigilance over one's body require energy often redirected from social relationships and 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, acidic cloth is in constant contact with women's sensitive skin. Several women explained how using pads results in chafed and discolored inner thighs. 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 unappealing options: visible leakage or invisibility but chronic pain. Most women (usually those living without co-wives who have more privacy) preferred not to wear pads when at home, reserving them for when they needed to venture beyond their compound's protective walls.

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 their intake of liquid (and sometimes food), resulting in or exacerbating existing nutritional deficiencies in iron and vitamin A, and causing fatigue, pain, and general malnutrition. Additionally, in Niger, when temperatures soared above 100 degrees Fahrenheit much of the year, the regular restriction of water can cause chronic dehydration. Dehydration (in conjunction with infection and diets low in protein and vitamin A and B, but high in fat and salt) commonly results in the formation of bladder stones, or crystallized masses of minerals found in urine. Bladder stones cause women abdominal pain and painful urination (as well as more serious health problems), and often must be surgically removed before women are able to undergo fistula repair surgeries. In the neoliberal healthcare terrain of Niamey, within which fistula care is commoditized and outsourced to visiting teams of foreign surgeons, the women I interviewed waited an average of six months and up to six years on hospital grounds to receive operations (see Heller 2017). Surgeries were maddeningly infrequent; long waits and protracted absences from home had serious consequences on women's social lives, often resulting in divorce and the attenuation of social bonds. The formation of a bladder stone, which must be surgically removed before fistula repair operations can be attempted, further prolongs the stay at a fistula center by months or even years.

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 Amira (40, Hausa) who had hidden her fistula for fifteen 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 spray them with perfume before anyone else in the household woke up for morning prayer. Fifteen years of vigilant self-care. Fifteen years of new hiding places for soiled rags. Fifteen years of fasting. "*Ina jin kadaici*" (I feel loneliness), Amira admitted. Yet, for Amira, loneliness was a small price for passing, "To look like everyone else, to seem like everyone else.... I'm not a woman anymore...but, to others, at least I look like one."

For women like Amira, concealment work replaces, or at least reduces, the embodied experience of shame and (real, potential, or feared) mistreatment associated with fistula with the emotional toll of isolation and anxiety. Women who pass are often emotionally isolated with few companions to share in their burden, and physically alone, as the social ramifications of concealment are often the weakening and reduction of social ties.

Women who are able to conceal the symptoms of their fistula (most notably incontinence) were able to enjoy a certain 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,” although often at a social cost, allowances are made whereby the sick individual can avoid the responsibilities and obligations expected of non-sick members of society. Through concealment, women were able to avoid the “sick role,” and women’s relationships to their conditions become a largely interior process, whereby they struggled internally while attempting to appear “normal.” Yet, there are consequences to the trade-off of appearing normal while managing and concealing sickness. Rather than opting for one’s visible deviance, in this case incontinence, to be excused through a sanctioned means of illness, women who concealed their fistulas often appeared inexcusably socially deviant, as they could not fulfil attendant social obligations.

Laraba (27, Kanuri) explained that because of her fistula, she was reluctant to leave her home for any extended period of time out of fear 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 relationship 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, “[Laraba], 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, too.

After several years of concealing, Laraba felt as though she had few close connections. Few knew the reason behind Laraba’s apparent neglect, so it was not excused. Sadly, with a shrug, she repeated a common Hausa proverb, “*zumunta a kafa ta ke*,” (good relationships depend on one’s feet.)

The Invisibility of Concealment

I spoke with an administrator at the Danja Fistula Center—one of my field sites—who was present when *New York Times*’ Columnist Nick Kristof came a few months after I left to interview women with fistula (for a column about the center, see Kristof 2013). This administrator who translated for Kristof recounted how the journalist was interested in

speaking with women who had the most “powerful” stories. He handpicked one particularly young and beautiful girl but became frustrated with her answers, aborting the interview and never using her story. The administrator recalled:

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. ... the husband didn’t know, not even talking about the community! ... [Kristof] kept pressing that with the lady, but she kept just saying, “Nobody knew.” ... He didn’t believe it, and he’s not interested in that story.

After speaking with this young woman, the story Kristof (2013) ultimately wrote was about “humiliated women and girls with their heads downcast, feeling ashamed and cursed, trailing stink and urine.” Most women “have been sent away by their husbands, and many have endured years of mockery and ostracism,” he reported (Kristof 2013). Journalists, 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 Nicholas 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 here are exceptional in their steadfast resilience in the face of illness and self-management, I argue that small (but daily) acts of concealment are not the exception but are the norm.

While narratives of suffering highlighted by media and donor organizations focus largely on the external—the treatment women are subjected to by others—most women’s narratives of suffering focus largely on the internal (experienced as shame, loss of identity, and valuelessness). When women recounted their experiences, they talked about their embarrassment, the shame they felt, and the constant worry they endured wondering if they would ever get better.

In discussions of female incontinence in the Global North, the focus is on the ethos of the sufferer—her struggle to redefine her identity, her feelings of shame and betrayal by her own body—not the reaction of her social contacts (e.g., Lose 2005; Manderson 2011). The same is not true of women with fistula in Niger, where the discourse surrounding fistula tends to focus on forces external to the women: mistreatment from husbands and rejection from communities, often due to a perceived corrupted culture that valorizes only the reproductive capacity of women.

Yet, this persistent focus on the external fails to capture the daily struggles of Nigérien women with fistula. Women’s quotidian reality of fistula was dominated by internal battles of identity, emotional isolation, anxiety about passing, fear of outing, logistical complexities of concealment work and body management, physical discomfort, and relational repercussions of self-isolation and social distancing. In our understanding of fistula experience, these anxieties, tasks, and existential struggles are obfuscated by a dominant narrative

Figure 1. A woman with fistula who was hand-picked due to youth, beauty, and a young child holds donated items from a local organization while publically giving her thanks. She was not asked for consent to be televised from the donor organization.



of visibility, rejection, and social abuse. Such misperceptions result not only in ineffective interventions but may actually harm women.

The Landscape of Aid: Outing and Betrayed Confidentialities

Following more than a half century of neoliberal policies that have hollowed out Niger's states services, NGOs have proliferated across all sectors of Niger, filling in the wide gaps left by the receding state. In 1990, sixty NGOs operated in Niger; today more than 2,600 do (Soumana 2017). In the health sector, donor financing contributed nearly 30 percent of total expenditures in 2010 (World Bank 2013). This deep financial investment of international NGOs has, in turn, birthed countless local NGOs—counterpart organizations able to profit from the windfall. The financial incentives to profit from fistula results in routinized care practices oriented more towards maximizing income generation rather than best clinical or social outcomes. In the Nigérien fistula care industry, women's needs are continuously overlooked by both private and state-affiliated actors for whom potential fistula funds from donor agencies such as UNFPA, USAID, OXFAM, or the International Red Crescent may represent a local actor's best opportunities to not just scrape by, but to get ahead.

In an effort to increase public awareness of an organization (with the hopes that funding will follow), donation ceremonies become publicity events. Fabric (often emblazoned with the word “fistula”), soap, perfume, and other goods are given out to women with fistula. On donation days in Niamey, typically one or two women are asked to publicly offer

Figure 2. A fistula patient wearing fistula intervention fabric. In the large circle, it 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.



thanks to the organization, which is broadcast on television stations throughout Niger. At one Niamey donation ceremony, an administrator eyed the woman who volunteered, telling a center nurse, “No, she won’t do. We need someone younger and more beautiful.” Eventually a young and beautiful woman with a child was chosen as requested. The woman was not asked for her consent, nor were the implications of her participation explained. The young woman had been concealing her fistula from her community for two and a half years.

The gift of fabric (*pagne*, or *zane*) with fistula-related logos is a double-edged sword. 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. Women with fistula are often plagued by a perpetual scarcity of fabric due to their heavy use of cloth pads and the acidity of their urine that rapidly degrades their skirt wrappers. The gift of fabric is a welcome resource. Yet, as no woman I interviewed was literate, women may not be aware that these sartorial choices may advertise, or at least associate, them as women with fistula once home.

Women's confidentiality is also placed in jeopardy when women are accompanied back home by clinic staff following post-surgical reintegration courses. For some women, outing might be a cause of increased shame, embarrassment, or mild social tensions. For other women, particularly those who found themselves socially vulnerable before the development of their fistulas, community or household/spousal knowledge of their conditions can be a cause of significant social harm.

Aïshatou (27, Zarma) was healed of fistula. Yet, she had a precarious position within her household before the development of her fistula. The entire time she leaked, Aïshatou hid her fistula from her community members. However, after a successful repair surgery she was accompanied back to her village by health officers, a common prevention strategy of many fistula reintegration programs. Aïshatou recalled:

[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.

A startling implication of dominant donor and media narratives of fistula are the inherent assumptions that fistula is an all-defining trait that cannot be concealed. This assumption leads to fistula policy and programming that unintentionally threatens women's identities as *well* once home. Fistula centers frequently disregard women's confidentiality and choice to reveal (or conceal) their own health status. Through televised donation ceremonies, gifts of fabrics adorned with fistula-related logos, and accompaniment back home following the completion of reintegration programs, women's alibis for treatment-seeking are jeopardized, and their efforts at concealment and self-management are continually undermined. As one particularly outspoken female Nigérien obstetrician/gynecologist said at an international fistula conference: "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."

Applying Ethnographic Insight

Much of the thought surrounding the social consequences of fistula positions the condition itself as the driver behind the deterioration of women's social bonds, attributed largely to fistula-related social stigma. However, I have argued here that in an effort to mitigate internal processes of shame, embarrassment, and fear of mistreatment, women deploy myriad concealment strategies, many of which have the unintended consequences of eroding the strength and breadth of their social networks, leaving many women with fistula at an increased risk of social vulnerability. And yet, despite the high social, emotional, and physical costs of concealment, the vast majority of women with fistula continue to engage in fastidious self-regulation, concealing—often for months, years, or decades—their incontinence, conditions, ill health, or surgical failure. Perhaps women's concealment can be understood as both agentive innovation and improvisation and also a form of entrapment.

Despite the costs, concealment work was worth it for most women, as those who were able to conceal while also maintaining their social links and relational responsibilities were often able to sustain the vitality of their social networks.

Although women with fistula typically felt most comfortable limiting their social engagement and thus their risk of exposure, most acknowledged that it was these acts of sociality that anchored them most effectively in their communities and even their marriages.

If fistula centers and associated NGOs acknowledged the centrality of concealment in women's experience of fistula, they could substantially restructure intervention strategies in order to support (rather than undermine) women's efforts. For example, an increased focus on appropriate technologies to better manage incontinence (such as a urethral plug or modified menstrual cup) would offer women rapid and more effective methods to conceal. When women don't have to exclusively rely on methods prone to failure (such as fabric pads), they feel more comfortable leaving home and re-engaging socially. Reinforcing women's tools, techniques, and thus social confidence can be an effective method for mitigating stigma and promoting women's dignity.

At the very least, fistula centers should abstain from interventions that jeopardize women's identities within their communities and households as whole and healthy. Interventions must acknowledge women's concealment efforts and respect their choice to "pass" through an increased commitment to ongoing informed consent procedures. Routinized calls from fistula center staff to husbands or family members should be abandoned, replaced by an opt-in system. Additionally, centers might rethink televised donation ceremonies, abandon the use of branded fistula fabrics as gifts to women, and adopt an individualized approach to accompaniment back home, responding to each woman's specific needs and desires.

Practitioners and advocates for women's health work with limited resources to reshape the maternal health landscape. This is not an indictment of these devoted individuals. Rather, it is evidence that even among those working in the field of fistula prevention and treatment, concealment practices are still quite poorly understood and inadequately addressed. When public health interventions operate largely on an empowerment model (through interventions encouraging changes in behaviors and beliefs), there is some question as to whether funders would support such a pivot. However, a commitment to ethical fistula work in sub-Saharan Africa demands that the needs and desires of women themselves are the primary drivers of intervention design.

Notes

¹All names are pseudonyms.

²Concealment, the refusal of disclosure, in conjunction with these coping strategies, was acknowledged among women in Ethiopia and Uganda who hid their conditions from neighbors, relatives, and even husbands (Barageine et al. 2015; Gjerde et al. 2013). In a study of women with fistula in Tanzania, Watt and colleagues (2014) found that women went to "extreme efforts" to hide their conditions from their religious communities. Similarly, Hannig's (2015) research with nurse aides in fistula hospitals in Ethiopia demonstrates the lengths these former fistula patients-cum-hospital-employees go to in order to conceal their chronic incontinence and maintain the authority of a "healer."

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