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Unsettling the fistula narrative: cultural pathology, biomedical redemption, and inequities of health access in Niger and Ethiopia

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ABSTRACT

Obstetric fistula, a maternal childbirth injury that results in chronic incontinence, affects an estimated one million women in the global south. In the course of media and donor coverage on this condition, fistula sufferers have been branded as 'child brides' who, following the onset of their incontinence, become social pariahs and eventually find physical and social redemption through surgical repair. This narrative framing pits the violence of 'culture' against the potency of biomedical salvation. Based on over two years of ethnographic research at fistula repair centres in Niger and Ethiopia, this paper challenges this narrative and argues that most women with obstetric fistula remain embedded in social relations, receive continued familial support, and, unexpectedly, experience ambiguous surgical outcomes. This paper interrogates the existing logics of the fistula narrative that have had the unintended effects of obscuring global structural inequalities and diverting attention away from systemic health access reforms.

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Introduction

Obstetric fistula is a maternal childbirth injury that results from prolonged, obstructed labour that is unrelieved by an emergency medical intervention, such as a Caesarean section. The protracted pressure of the foetal head against a woman's pelvic tissues produces an abnormal pathway between the vagina and bladder and/or between the vagina and rectum, leading her to lose control over her urine or faeces, and sometimes both. It is estimated that over 85% of all fistula cases result in stillbirths (Ahmed and Holtz 2007). Women who sustain obstetric fistula also commonly suffer from secondary ailments, such as foot drop, bladder and kidney infections, limb contractures, or excoriation from the skin's constant exposure to urine or faeces. While obstetric fistula is extremely rare in resource-rich countries, it is said to affect an estimated one million women in the global south, most of whom live in sub-Saharan Africa (Adler et al. 2013).¹

Prior to the institutionalization of birthing, obstetric fistula was not uncommon in Europe and the United States. Starting in the seventeenth century, European doctors were first attempting to close obstetric fistulas, employing sutures made of swan quills, gold wire, and lead. Though not the first American surgeon to successfully close a vesicovaginal fistula, the physician Marion Sims has been widely credited with pioneering an effective, replicable surgical technique for repairing obstetric fistula cases. Between 1845 and 1858, Sims conducted medical experiments on enslaved black women with obstetric fistula in antebellum Alabama. Since these ominous beginnings, fistula repair has continued to undergo transformations. In sub-Saharan Africa, Drs Reginald and Catherine Hamlin developed their own techniques for operating on fistula cases in Ethiopia in the 1950s, eventually founding the first dedicated fistula hospital on the continent in 1975. Around the same time in West Africa, expatriate surgeons like Una Lister, Ann Ward, and John Lawson began repairing fistulas, soon followed by a cadre of non-Western surgeons all across the continent, such as Dr Mulu Muleta in Ethiopia or Dr Jonathan Karshima in Nigeria, along with many others.

Even though obstetric fistula has been identified and treated for some time, throughout most of the twentieth century, fistula was grouped with a host of other reproductive health issues. Only recently has the condition been singled out, receiving the focused attention of global media outlets and donor organizations. In the course of this coverage, a particular narrative has emerged around fistula. Fistula sufferers are typically said to be young girls forced into ‘child’ marriages and precocious pregnancies. In the wake of an unattended, protracted home labour—which leads to fistula—these girls are thought to be rejected by their husbands, abandoned by their kin, and exiled from their communities. Owing to their incessant leaking and its conspicuous smell, they are allegedly demoted to the status of social pariahs and relegated to the outskirts of their communities—despised and deserted. Fistula sufferers reportedly find salvation in a life-changing surgery that restores their continence and enables their return to society.

Despite some small variations, elements of this narrative can be located across the broad spectrum of popular media coverage (Winfrey 2005; Smith and Bucher 2007; Hedemann 2013), the donor literature (Hamlin 2001; Little 2010; Operation Fistula 2015), and many academic and medical publications on fistula (Kabir et al. 2003; Brugière 2012).² Prior to their surgery and on account of their debilitating injuries, women plagued by fistula are reported to face ‘a fate worse than death’ (Winsor 2013). Perhaps most strikingly, fistula sufferers have been branded the ‘the most wretched people on this planet’ (Kristof 2009).

As ethnographic researchers independently entering their respective field sites in fistula centres in Niger and Ethiopia, the authors, too, initially took the main tenants of this tale at face value. Heller and Hannig fully expected to meet young women—heavily stigmatized, largely abandoned—who were finding corporeal and social redemption through surgical interventions. Both of their initial project designs were, to some degree, premised on such assumptions. Yet, what they found over the course of a combined 2.5 years of ethnographic field research in two distinct African contexts fundamentally unsettles the foundation of this narrative. While most of the women the researchers met were struggling with a condition that could be physically and emotionally painful, they found that these women did not struggle alone. Though fistula certainly complicated their relations to kin and community, these women had not suddenly become social pariahs. Comparing notes, Heller and Hannig began to take a closer look at the template of the iconic narrative and its latent assumptions.

Using the tools of qualitative ethnographic observation and analysis, in this paper, the authors think through some of the logics that underwrite the existing humanitarian and media narrative about fistula. This paper suggests that the iconic profile of the fistula sufferer has gained such traction because its elements feed on long-standing patterns of pathologizing ‘culture’ in the global south, particularly in sub-Saharan Africa. This engagement identifies ‘harmful culture’ as the culprit for women’s reproductive despoilment and relies on Western—often biomedical—intervention to correct these injustices. The core elements of the fistula story pit the alleged violence of ‘culture’—premature marriage and the subjugation of women—against the potency of biomedical salvation. In contrast to this framing, the authors argue that women with obstetric fistula remain embedded in social relations during their affliction, receive continued familial support, and—strikingly—experience ambiguous surgical outcomes. In the limited space available here, Heller and Hannig show how women with fistula navigate the social implications of injury, within and without the framework of biomedical interventions.

These insights span two very different research contexts in Africa: a Sahelian, predominantly Muslim, West African setting where women mostly marry into polygamous unions versus a mountainous, largely Orthodox Christian, East African setting where monogamy is the norm. Heller conducted fieldwork at four fistula centres between 2011 and 2014: three in Niger’s capital of Niamey, and one located about 500 miles east of the capital in the rural area near Maradi. Her research subjects belonged to six ethnic groups and came from across Niger as well as Nigeria and Mali—the largest proportions self-defined as Hausa, Zarma, Tuareg, and/or Fulani, and all identified as Muslims. Hannig carried out ethnographic fieldwork at the Hamlin fistula centre in Bahir Dar in the north-west Amhara region and at a fistula rehabilitation centre near Addis Ababa, Ethiopia’s capital, between 2008 and 2010. The majority of her interlocutors self-identified as Amhara and as Ethiopian Orthodox Christians; a smaller minority adhered to Muslim or Protestant Christian faiths, and some of her contacts identified as Oromo, Sidama, or Tigrayans. Despite these considerable ethnic, geographical, religious, and cultural divergences, both within and between Niger and Ethiopia, the authors noticed striking similarities in the ways that women with fistula faced obstetric complications; how their communities, kin, and husbands reacted to their incontinence; and how they tried to manage this sudden disruption in their lives. Their stories not only unhinge the existing narrative on fistula, but can also tell us something about how bodily affliction is embedded in larger social worlds.

Spectres of cultural pathology

In his theoretical work on narratives, Jerome Bruner (1986, 11) contends that narratives offer a way of ‘ordering experience, of constructing reality’. In telling stories, as Mattingly and Garro (2000, 11) argue along similar lines, ‘narrators moralize the events they recount and seek to convince others to see some part of reality in a particular way’. Narratives, then, not only mirror perceptions of reality, but actively fashion it. In global humanitarian and medical settings, telling an effective narrative allows public institutions and the individuals they serve to tap into volatile currents of global funding and attention (Malkki 1996; Butt 2002; Nguyen 2010; Fassin 2012). At the same time, these narratives have helped construct particular types of realities that have had concrete, real-world repercussions.

Popular accounts of fistula are part of a longer history of representations of Africa and Africans as steeped in 'tradition' and dysfunction. In an effort to 'create moral categories that connect those who help the needy with those who are in need' (Bornstein 2005, 171), these accounts have contributed to well-worn portrayals of Africans as irrationally bound by 'culture'. In the context of a continent routinely viewed 'through a series of lacks and absences, failings and problems, plagues and catastrophes' (Ferguson 2006, 2), we must scrutinize such portrayals with special care.

The idea of identifying 'culture' as a culprit for illness and mortality has a long history on the African continent (see Burke 1996; Comaroff and Comaroff 1997; Hunt 1999). In colonial East and Central Africa, writes Vaughan (1991), the language of cultural difference steadily supplanted a focus on economic and environmental causes for disease. 'Susceptibility to disease in Africans, then, was defined not through an analysis of the conditions under which they lived and worked', notes Vaughan (1991, 46), 'but rather through the idea that the cultural practices of different ethnic groups disposed them to various disease patterns'. A similar preoccupation with 'unenlightened culture' can be found at the heart of the contemporary notion of 'harmful traditional practices' (Dorke-noo 1994; United Nations 1995). This discourse, which includes indictments of female genital modification, polygamy, or wife seclusion, is highly gendered, focusing almost exclusively on women's bodies, particularly around reproduction.

Similarly, representational practices for fistula have largely focused on giving an account of cultural—rather than political or economic—shortcomings. 'Culture' first intervenes when the woman is a mere child, encouraging her premature sale into conjugal life; then during labour, when 'cultural' norms that encourage birthing at home or alone keep the woman from appropriate medical care; and, finally, after the development of her fistula, when understandings of corporeal purity and reproductive success allegedly result in her degeneration into a social non-entity. These 'cultural' failings are juxtaposed to the potency and efficacy of fistula surgery, imagined to succeed in returning the woman to a life worth living. This focus on pathological 'culture' has fashioned a reality in which the structural dimensions of how women sustain obstetric fistula and how they navigate their injury have become obscured. As a result, the solution to the problem of fistula seems to lie in reforming cultural habits, such as 'child' marriage, rather than instituting complex health access reforms.

This paper dissects the three main tropes that reside at the centre of current depictions of women with fistula: the despoiled child bride, the social pariah, and the idea of the quick, surgical cure. In juxtaposing these tropes to the accounts of women with fistula encountered during the authors' respective research, a more complicated image emerges.

The despoiled child bride

The standard narrative positions 'culture' as the primary culprit responsible for mothers sustaining fistula. The narrative zeroes in on a particular type of fistula sufferer: she is young, innocent, and physically underdeveloped. Those with fistula are rarely portrayed as women, but widely referred to as 'girls'. The fistula narrative routinely focuses on 'child' marriage as a principal cause of obstructed labour, resulting in pregnancies among girls whose pelvises are too small and 'immature' to birth a fully developed child (Wall 1998). For example, Catherine Hamlin, co-founder of the first fistula hospital in Ethiopia, links

fistula to the practice of ‘child’ marriage in her writings: ‘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’ (Hamlin 2001, 130).

This focus on girls plays into a Western preoccupation with the innocence of children and the moral panic surrounding their sexuality and sexual exploitation, which has intensified since the 1980s (Lancaster 2011). Invoking images of abused, despoiled, or tainted youth, fistula is then framed as the physical evidence of corrupted ‘cultural’ practices—of children who are no longer allowed to be children, as they are drafted into marriage and its onerous duties. The narrative’s emphasis on first pregnancies means that the young girl is left without living children, leaving her alone and without value in cultures portrayed as aggressively pronatalist. 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).

During their research the authors found that women in Niger and Ethiopia are indeed often married before the age of 16. And yet, the connection between these marital conventions and the development of obstetric fistula is tenuous. First, women develop fistula throughout their reproductive life spans, representing a wide range in age and parities. Women the authors came to know in Niger and Ethiopia sustained their fistulas anywhere from their 1st to their 12th pregnancies, when they ranged in age from 13 to 54. Surgeons and researchers have readily and frequently acknowledged that fistula can occur during any birth (Maulet, Keita, and Macq 2013). Yet, this diversity is often glossed over in global representations of fistula, which remain fixated on ‘child’ marriage and first-time mothers, a framework that works to further semiotics of cultural failure rather than depicting meaningful causal relationships.

Second, even if sexual activity commences in a woman’s mid-teens, this pattern is not unique to countries like Niger or Ethiopia, but mirrors global trends of adolescent sexual activity (Mosher, Chandra, and Jones 2002). The United States, for example, witnesses a relatively high number of teenage pregnancies each year, yet obstetric fistula very rarely occurs because these teenagers can avail themselves of emergency obstetric care in the event of birthing complications (as scholars such as Kabir et al. [2003] have also noted). This suggests that the prevalence of obstetric fistula is not forcibly a function of age, but rather the lack of access to quality emergency obstetric care.

Third, the authors’ ethnographic material suggests that ‘child’ marriage does not necessarily lead to early pregnancy, as women who are married young often experience an extended period of sexual abstinence following marriage. For example, Rashida, a 21-year-old Zarma woman from Niger was married at the age of 14, but did not become pregnant until she was 20.³ She explained, ‘If a 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’. In north-western Ethiopia, in a so-called *giyyid* union, the bride and groom marry when they are often between 5 and 10 years old, but must abstain from sexual relations until a date set by a priestly or elderly contract, usually until the girl turns 16. As 23-year-old Genet from the Amhara region recalled: ‘The wedding and the feast took place when I was ten, but we didn’t start living together until after I had finished school, around twenty.

We started having intercourse then and after two years I got pregnant'. Youth marriage thus takes place within a context of social conventions that regulate young women's sexuality while concomitantly protecting them until they are thought to be 'ready' for sex, pregnancy, and motherhood.

The social pariah

The ostensible violence of 'culture' continues once a woman sustains fistula. Following the onset of her incontinence, she is said to be shunned and isolated by kin and community, divorced from her husband, and relegated to a distant hut on the outskirts of her village. Women with fistula are widely reported to become social outcasts. Common newspaper headlines read: 'Surgery saves pathetic outcasts' (Gordon 1975); 'New Life for the Pariahs' (Kristof 2009); or 'Die Ärztin der Ausgestoßenen' (Doctor of the outcasts) (Hedemann 2013). *New York Times* columnist Nicholas Kristof (2005) describes the social death of women with fistula thus:

Her husband normally abandons her, the constant trickle of urine leaves her with terrible sores on her legs, and if she survives at all she is told to build a hut away from the rest of the village and to stay away from the village well. Some girls die of infections or suicide, but many linger for decades as pariahs and hermits.

In the course of this narrative of isolation and abandonment, fistula is linked to other afflictions that carry symbolic power. Women with fistula have, for instance, been coined 'the lepers of the 21st century' (Kristof 2009). As Operation Fistula states, 'the bright eyes and big smile that [a woman with fistula] once had are replaced by the pain and loneliness that only a leper can know' (Operation Fistula 2015). Even though fistula is not seen as contagious in the way leprosy once was, links with leprosy evoke powerful images of grotesque bodies, social stigma, and spatial separation. Through the comparison with leprosy, the alleged social ostracization of women with fistula gains heightened metaphorical weight, adding to the perceived severity of the condition.

The following subsections complicate the image of the social pariah by examining fistula's cascading effects on women's marital, familial, and social lives, paying particular attention to ethnographic texture and variation.

Conjugal uncertainty

The iconic narrative depicts fistula sufferers who have been deserted by their husbands following the onset of their incontinence. Yet, many women with obstetric fistula find themselves in a liminal phase of sorts—not technically divorced, but often not living with their husbands either. Most women in Niger and Ethiopia deliver at their parents' and not their marital home. In cases of a birthing injury, women frequently remain at their parents' home because they are reticent to return to their marital household (and attendant responsibilities) until they have convalesced. These postpartum absences of 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', her prolonged absence from her husband begins to take on a deeper significance.

Rabi, a 25-year-old Zarma woman in Niger who had lived with fistula for three years and had undergone four surgeries, expressed 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 [my husband's] house. He comes to visit me at my parent's house, but he does not give me money. 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.

Lemlem, an 18-year-old student from the Amhara region in Ethiopia who was married to another student, was staying at her family's home after her failed delivery. Her father told her husband who came looking for her, 'If you want her back, cover the cost of the clinic', to which her husband responded, 'I can't afford it, I am still a student. She can come back and live with me, but if she doesn't, she can live with you'. After the onset of fistula, both husband and wife are forced to re-examine their marital configuration, constantly recalculating the costs versus benefits of possible futures.

For some, fistula does indeed result in divorce and diminished marriage prospects, as it can serve to exacerbate already existing power differentials. For instance, in Niger, if a woman who is a co-wife sustains a fistula, the other wife might use this development to position herself advantageously *vis-à-vis* their husband. Salamatou, a 47-year-old Hausa woman from Niger who lived with fistula for 30 years, attributed her divorce not to her husband's disgust at her fistula, but to the tensions between her and her co-wife: '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"'. Despite Salamatou's long-standing supportive relationship with her husband, her co-wife eventually undermined her social power within her household.

Other women make the decision to leave their husband's home of their own accord. For example, in Ethiopia, some husbands would periodically show up at their in-laws' house and implore their spouse to return to the marital household. 'My husband used to come to my home at night and beg me to come back to him', 26-year-old Kebra from Tigray related, 'but I told him I didn't want to live with him anymore'. Kebra said she felt torn between affection for her husband and a deep shame about her condition. In other cases, women deliberately capitalize on periods of conjugal uncertainty. Some blame their husband for their injury or are angry at his lack of care; others use fistula to liberate themselves from unhappy marriages. For example, Sa'a, a 27-year-old Tuareg-Zarma woman from Niger who was married against her will at 11, 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'. When asked how the divorce made her feel, 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.

Ironically, it is often fistula treatment itself that can have the unintended side effect of inaugurating a marital rift. In Ethiopia, a patient's treatment sometimes requires her to return to a fistula centre sporadically for new operations, causing an unwelcome strain on the marital bond and leading some husbands to eventually opt for divorce. 'My husband stayed with me for six months', Assada, a 23-year-old Amhara woman who had been in and out of the Addis Ababa Fistula Hospital for years, recounted. 'Then, he married another woman. At that time, I was at the hospital and I was returning frequently for

more treatment, so I told him to marry another woman'. But whereas fistula treatment in Ethiopia is quite efficient (the average stay at the Bahir Dar fistula centre was under three weeks in 2010), women with fistula in Niger had stayed an average of five months at their respective clinic in 2013, and as long as six years without having received an operation.

In Niger, many clinics, particularly those that are not exclusively dedicated to fistula repair, have tremendously long backlogs. Rather than sending women home until their scheduled operation, clinics prefer to have women wait at the centre—so women wait, sometimes years. For instance, Zara, a 29-year-old Hausa Nigerien woman who had been at a fistula centre for nine months, explained that her decision to seek treatment resulted in her divorce from her 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"'. Although Zara's husband accepted her incontinence, he refused to accept her prolonged absence from his household. In these cases and many others, it was the treatment for fistula—rather than the injury itself—that led to a deterioration in marital relations.

It is, however, not inconceivable that a husband would stay with his wife and see her through the period of her injury or await her return home from the hospital. While accounts of husbands washing the urine off their wife's body, cleaning her clothes, consoling her, or fetching water and firewood were perhaps not the norm, they were also not exceptional. Such was the case with Kidist, an Amhara woman of 18 from Ethiopia: 'When people gossiped about me in front of my husband or tried to separate us, he would say, "When I married her, she was a healthy woman. I am not going to leave her now that she is sick"'. Similarly, Naio, a 29-year-old Zarma woman from Niger, said that when she developed fistula following her sixth pregnancy, her husband supported her, sleeping in hospital courtyards for months: 'Every day, he would bring me food, wash my body, wash my clothing. He even washed the rags I used for the urine. ... My husband, he tries his best. ... He is a good man'.

Given the relative ease with which conjugal relations can be severed in both Niger and Ethiopia, these testimonies of caregiving and fidelity are striking. They show that women with fistula may benefit from the support of their husbands and retain a significant degree of control in their conjugal futures even amidst periods of uncertainty. The reductionist typologies of marital abandonment forwarded by the donor and media fistula narrative transmit little texture of these complicated conjugal experiences.

Self-regulation and concealment

During their research the authors never encountered a patient who—owing to her condition—had been deserted by her kin and put outside her community. Contrary to the image of the social pariah who is defined by her spatial segregation, women's experiences of separation were small acts of self-regulation. Women often reported moving rooms in the same house or sharing a room (and often a bed) with an older or younger female relative rather than with their husband. While, for some women, fistula did result in weakened social relationships and mistreatment by neighbours, kin, or husbands, others shared accounts of kin stepping up to provide for them, generous neighbours, and fathers who sold their last cow to afford the fees for a hospital transport. The vast majority of fistula patients the authors worked with did not report experiencing overt discrimination.

Rather, their decision to withdraw from social functions originated from their own feelings of shame of their leakage and its accompanying smell.

Although the donor and media narrative portrays fistula as an eminently visible marker of a woman's identity, most women the authors came to know made significant efforts to maintain control over the information others had about their condition. Women with fistula invested 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 gossip of community members. For many women, only their immediate family knew about their incontinence (and in Niger several women succeeded in concealing their fistulas for several years even from their husbands). Women hid their condition through strategies such as the use of fabric pads, fastidious standards of cleanliness, frequent changes of clothing, selective fasting, and using perfume to cover odours.

In Niger and Ethiopia, women's attempts to 'pass' as continent frequently came at a cost to their personal relationships, social status within their communities, emotional health, and economic stability. For instance, Kedija, a 35-year-old Muslim woman from the Amhara region of Ethiopia, expressed feeling very self-conscious about her condition: 'My neighbours would call me over for coffee, but I didn't go because I didn't want to leak urine all over. I just stayed at home because if someone had told me that I stink I would have gone mad. I asked Allah why he had given me this disease. I wish it had been another disease that wouldn't have prevented me from socializing with my friends'. Women who conceal their fistulas often appear socially deviant, as they cannot fulfil reciprocal social obligations. Because Aissa, a 27-year-old Hausa-Zarma woman from Niger, was reluctant to leave her home for fear of leaking, she began to neglect her social obligations. 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'. But only I know why... [My friends] don't come very often anymore to see me. If you stop visiting someone, that person will visit you less.

After several years of concealing her leaking, Aissa felt as though she had few close connections left. Resigned, she repeated a common Hausa proverb, '*zumunta a kafa ta ke*'—good relationships depend on [one's] feet.

These women expressed a similar sentiment: self-isolating provided them some distance from the humiliation they might experience if others saw them leaking or smelled their urine. Women with fistula often engaged in systematic social distancing, 'opting-out' of social commitments in order to protect their identities as 'well'.

Despite their quotidian challenges, the authors found that if a woman with fistula was adept at maintaining her social links by participating in reciprocal relationships and community events, she was able to remain integrated in her social circle. Hodiye, an Amhara woman in her 40s, carefully managed her time when attending social functions: she would only stay for the first of three customary rounds of coffee at her neighbours' house for fear that the leaking would suddenly start. When someone in her community passed away, she avoided the wake during the first couple of days, which drew a dense crowd, and instead came on the third or fourth day, when there were fewer people in attendance. If asked why she had come late, Hodiye would allege that she had only just heard about the death. Although women with fistula tended to feel apprehensive about placing themselves in

close proximity to others unaware of their condition, it was precisely these acts of sociality that anchored them most effectively in the fabric of their communities and that protected them from the potentially negative consequences of fistula.

Surgical salvation

Most representations of fistula position surgical repair as the release from a woman's life of loss and devastation: the hospital symbolizes a place of both healing and rebirth. There, an ailing woman is relieved of her incontinence through a simple operation and emerges reborn, 'like a butterfly from the chrysalis' (Hamlin 2001, 282). Surgery for fistula is routinely portrayed as a quick and easy 'fix'—a technocratic solution akin to vaccinating children or handing out mosquito nets (IRIN 2009). In part, it is the alleged ease but enormity of impact in a case like fistula—a \$400 surgery that takes no more than two hours, and often as little as 20 minutes—that has made pledging money to its cause so palatable for donors.

Contrary to widespread claims about the high success rate of fistula surgery—which is said to restore continence in over 90% of cases (Engender Health 2014; Fistula Foundation 2014)—surgical interventions are less effective than commonly imagined. In Niger, when women are finally able to secure surgeries after long waits, Heller found that these operations are frequently unsuccessful. Of the 61 women who underwent surgery during the clinical stay at which they were interviewed, only 36% attained continence, while 64% remained incontinent. Such poor outcomes are seldom reported.⁴ As one medical assistant 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'.

Mariama, a 35-year-old Hausa woman who had undergone four previous surgeries, explained why after her first two operations, she made the decision to stop seeking care for almost two decades. She said that after two years of constant travelling between her home and the hospital, long waits on hospital grounds, and ultimately nothing to show for it, 'I decided that since the two surgeries didn't work, I would stop searching for surgeries. So, I went home and decided to stay like this'. Although she developed fistula during her first pregnancy, Mariama lived with her husband and co-wife for over 20 years with fistula, having eight more pregnancies and raising four children, before deciding to seek care again.

Fistula surgeons themselves have increasingly recognized that fistula repair is not the straightforward fix it has largely been made out to be. Many patients previously thought to be 'cured' are in fact not so. For many women, their fistula may be closed following an operation, but they still suffer from so-called residual urinary incontinence. As Dr Browning, former fistula surgeon in Ethiopia, put it: 'We're very good at closing the hole. But making people continent by reconstructing all the continence mechanisms is a completely different matter. And that's the challenge of fistula surgery' (cited in Little 2010, 190). A rare follow-up study conducted by the Bahir Dar fistula centre in Ethiopia found that 31% of those who had previously been discharged as 'cured' had developed residual urinary incontinence and that in another 9% the repair had broken down (Browning and Menber 2008). Despite medical practitioners' growing awareness of the potential chronicity of fistula, this knowledge has not yet found its way back to global fistula awareness campaigns.

Accessing emergency obstetric care

The elements of the iconic fistula narrative—the despoiled child bride, the social pariah, and the idea of surgical salvation—have displaced a focus on structural inequalities of multiple scales in favour of condemning local ‘cultural’ inadequacies. While the narrative situates fistula as the consequence of unenlightened ‘culture’, oppressive patriarchy, and neglectful families, it elides the fact that fistula is deeply enmeshed in geopolitical priorities, structural adjustment policies, and legacies of colonization and post-colonization, which have crippled local economies and public services in the global south. As one visiting British gynaecologist who was being trained in Ethiopia to perform fistula surgeries in Ghana commented, ‘It is easier to get funding for fistula treatment than it is to raise money for more hospitals with maternity wards.’ Thus, the highly stylized tragedy that surrounds the fate of fistula sufferers is fundable, while the appeal to increase access to emergency obstetrics is less so.

Even though there is some acknowledgment in the literature that women’s access to hospitals is inadequate during labour (Mselle et al. 2011), giving birth at home is still framed as a cultural—rather than a structural—failing. Women themselves, or their families or husbands, are often blamed in the development of fistula; they are judged to cling too tightly to ‘traditional’ birthing practices and ideas about privacy and pride that allegedly inhibit accessing timely biomedical care. In order for a system of health infrastructure to take root in sub-Saharan Africa, David (2013) argues, ‘we need to continually pay attention to limiting cultural beliefs and behavioural patterns that stop local and uneducated women from using health facilities’. In arguments such as these, birthing in a medical facility is framed as the solution to fistula prevention.

And yet, in both Niger and Ethiopia, most rural health facilities are burdened by chronic shortages of trained personnel, drugs, equipment, ambulances, electricity, and running water, and are unable to perform C-sections in the event of obstructed labour. According to Ethiopia’s latest Demographic and Health Survey, roughly 0.5% of rural births are delivered by Caesarean Section (CSA 2012, 128). And even though 82% of Niger’s population lives in rural areas, only 19% of nurses, 8% of midwives, and 0% of doctors work in rural areas (République du Niger 2011). Although the assumption is that women with fistula have waited a dangerously long time at home, this is not always the case. While some women interviewed did spend days in labour at home without reaching out for biomedical care, many others reported heading to their local clinic as soon as their labour began. They tried to deliver at health centres, but experienced poor medical treatment, including referral delays, refusal of services, physical and verbal abuse, inappropriate interventions, and botched Caesarean sections and episiotomies.

For example, Lahiya, a 26-year-old Hausa woman from Niger had a large fibroid that obstructed her labour for three days. The government-trained midwife in her local health centre 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’, delaying her referral to a higher level of care for four days, until she became unconscious and developed fistula. Yeshe, an Amhara woman in her early 20s, had made three prenatal visits to her local clinic during her second pregnancy. When her labour turned out to be obstructed and she went to the clinic, she received a glucose injection and was told that nothing else could be done for her there. Upon her arrival at the distant district hospital hours later, a physician extracted the lifeless body of her baby.

The experiences of women like Lahiya and Yeshi illustrate that access to care is not the same as access to quality care. Fistula can be caused by an inadequately trained clinician keeping a woman at a clinic for too long, refusing to refer her to a higher level of care, or performing forceful and inappropriate interventions in the face of an obstetric complication. According to estimates by the Addis Ababa Fistula Hospital, 11% of all fistulas in Ethiopia are caused by doctor malpractice; more broadly, the number of fistulas caused by biomedical provider error appears to be on the rise (Raassen, Ngongo, and Mahendeka 2014). Women's *perceptions* of biomedically-caused fistulas may be even higher, fuelling fear of seeking timely care during obstetric complications. In Niger, nearly a third of women interviewed by Heller believed that their fistulas were caused by healthcare providers. Hasana, a 27-year-old Zarma woman from Niger, explained that everyone in her community blamed medical practitioners for her condition:

People in my village said that it was the nurses that hurt me during the labour—that caused my sickness. ... They say, “Hasana went to the centre to give birth, but came home with fistula!” So, they won't give birth at the centre. They will only birth at home.

Yet, the assumption is that the fewer women who birth at home, and the less time they spend there, the better maternal and child outcomes will be. As a result, public health campaigns across sub-Saharan Africa disproportionately focus on 'raising awareness' and discouraging home-births rather than improving the breadth and quality of services offered at biomedical health centres.

Conclusion

The most recent of a long line of cultural interventions, global involvement in fistula advocacy and programming has become a *cause du jour*, receiving wide coverage and attention. In this paper, we explore how popular depictions of women with fistula identify pathological 'culture' as a culprit for women's childbirth injuries and subsequent social and familial mistreatment. Against the backdrop of 'harmful culture', biomedical intervention in the form of surgery has been framed as a means to both physical and social salvation. Yet, as the paper argues, not only do most women with fistula not fit within the narrative's archetype, but they continue to have fulfilling social relationships, remain entangled in networks of obligations and attachments, and manage relatively normal lives for decades while living with fistula.

For most women in Niger and Ethiopia, their stories lack the dramatics of those highlighted by fistula campaigns and media articles. Still, life with fistula *is* difficult. It is physically uncomfortable and emotionally taxing. Fistula complicates lives, reduces well-being, causes social anxiety, and results in many women trying to manage their shame by staying home. As a result, women often limit the time they spend with friends, conceal their conditions, reduce the amount they eat or drink, and practise various other forms of strict self-management. But even though fistula brings with it considerable social and physical handicaps, the prevailing narrative of exclusion is too simple.

Framing a health condition like fistula as a cultural issue has had the unintended side effect of diverting attention away from both sustained health infrastructure reforms and the politico-economic systems within which these inequities emerged. This problem extends well beyond the specificity of fistula and applies to other global health initiatives whose

focus on cultural inadequacies and individual behaviours obscures vast structural inequalities. For example, such patterns are reflected in the recent global response to the Ebola epidemic in West Africa, where burial practices and other local customs came under intense scrutiny, sometimes to the exclusion of more relevant risk factors. Subsequent attempts to transform ‘pathological’ cultural practices are bound to miss the mark, producing Band-Aid fixes rather than systemic solutions. As the authors’ broader work shows, there is a lot to be gained from a situated, long-term, ethnographic analysis that takes seriously the complex structural obstacles faced by those who experience illness and injury, while also understanding that their lives do not cave under the force of these constraints.

Notes

1. Prior WHO estimates of fistula prevalence—two million women—are now considered an overestimate. This paper focuses specifically on obstetric fistula, meaning fistula developed during labor. The authors recognize that vaginal fistulas are sometimes the result of traumatic injury, such as rape, or local treatments for ethno-medical conditions such as *yankan gishiri* in northern Nigeria, or *‘dan guriya* in Niger, where razor blades are used by village surgeons to expand vaginal canals.
2. There are some notable exceptions to this framing (see, for example, Bangser et al. 2010; Landry, Frajzyngier, and Ruminjo 2013; Phillips, Ononokpono, and Udofia 2016).
3. To preserve the privacy of our contacts, this paper only uses pseudonyms or omits proper names.
4. There are, however, recent exceptions (see Maulet, Keita, and Macq 2013)

Ethical approval

Both authors conducted research in line with the ethical perimeters of the institutional review boards at their home universities and their field sites. Heller secured approval from the Institutional Review Board of Washington University in St. Louis, le Comité Consultatif National d’Ethique du Niger, and le Ministère des Enseignements Moyen et Supérieur et de la Recherche Scientifique du Niger. Hannig received ethical approval from the Social and Behavioral Sciences Institutional Review Board at the University of Chicago, the Ministry of Education in Ethiopia, and the Ethical Review Board of the Addis Ababa Fistula Hospital.

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References

- Adler, A. J., C. Ronsmans, C. Calvert, and V. Filippi. 2013. "Estimating the Prevalence of Obstetric Fistula: A Systematic Review and Meta-analysis." *BMC Pregnancy and Childbirth* 13 (246): 1–14.
- Ahmed, S., and S. A. Holtz. 2007. "Social and Economic Consequences of Obstetric Fistula: Life Changed Forever?" *International Journal of Gynaecology and Obstetrics* 99: S10–S15.
- Bangser, M., M. Mehta, J. Singer, C. Daly, C. Kamugumya, and A. Mwangomale. 2010. "Childbirth Experiences of Women with Obstetric Fistula in Tanzania and Uganda and Their Implications for Fistula Program Development." *International Urogynecology Journal* 22: 91–98.
- Bornstein, E. 2005. *The Spirit of Development: Protestant NGOs, Morality, and Economics in Zimbabwe*. Stanford, CA: Stanford University Press.
- Browning, A., and B. Member. 2008. "Women with Obstetric Fistula in Ethiopia: A 6-Month Follow-up After Surgical Treatment." *British Journal of Obstetrics and Gynaecology* 115: 1564–1569.
- Brugière, M. 2012. "Obstetric Fistulas in Mali, Combating Maternal and Child Mortality." *Field Actions Science Reports*, Special Issue 5. <http://factsreports.revues.org/2707>
- Bruner, J. 1986. *Actual Minds, Possible Words*. Cambridge, MA: Harvard University Press.
- Burke, T. 1996. *Lifebuoy Men, Lux Women: Commodification, Consumption, and Cleanliness in Modern Zimbabwe*. Durham: Duke University Press.
- Butt, L. 2002. "The Suffering Stranger: Medical Anthropology and International Morality." *Medical Anthropology* 21 (1): 1–24.
- Comaroff, J., and J. Comaroff. 1997. *Of Revelation and Revolution: The Dialectics of Modernity on a South African Frontier*. Vol. II. Chicago, IL: University of Chicago Press.
- CSA [Central Statistical Agency]. 2012. *Ethiopia Demographic and Health Survey 2011*. Addis Ababa: Central Statistical Agency.
- David, G. K. 2013. "Culture, Tradition and Maternal Mortality in Africa." Campaign on Accelerated Reduction of Maternal Newborn and Child Mortality in Africa. <http://www.carmma.org/update/culture-and-traditions-role-maternal-mortality-africa>
- Dorkenoo, E. 1994. *Cutting the Rose. Female Genital Mutilation: The Practice and Its Prevention*. London: Minority Rights Publications.
- Engender Health. 2014. "Surgical Repair and Rehabilitation." <http://www.fistulacare.org/pages/what-is-fistula/surgical-repair.php>
- Fassin, D. 2012. *Humanitarian Reason: A Moral History of the Present*. Translated by Rachel Gomme. Berkeley: University of California Press.
- Ferguson, J. 2006. *Global Shadows: Africa in the Neoliberal World Order*. Durham: Duke University Press.
- Fistula Foundation. 2014. "Fast Facts and FAQ." <http://www.fistulafoundation.org/what-is-fistula/fast-facts-faq>
- Gordon, A. 1975. "Childbirth Ruins Their Lives in Remote Villages, But... Surgery Saves Pathetic Outcasts." *New Zealand Women's Weekly*, February 17.
- Hamlin, C., and J. Little. 2001. *The Hospital by the River: A Story of Hope*. Oxford: Monarch Books.
- Hedemann, P. 2013. "Die Ärztin der Ausgestoßenen [Doctor of the Outcasts]." *Sächsische Zeitung*, March 10.
- Hunt, N. R. 1999. *A Colonial Lexicon of Birth Ritual, Medicalization, and Mobility in the Congo*. Durham: Duke University Press.
- IRIN [Integrated Regional Information Networks]. 2009. "Cote D'Ivoire: Fistula – Two-Hour Operation Corrects Decades-Long Affliction". April 7. <http://www.irinnews.org/report/83840/cote-d-ivoire-fistula-two-hour-operation-corrects-decades>
- Kabir, M., Z. Iliyasu, I. S. Abubakar, and U. I. Umar. 2003. "Medico-Social Problems of Patients with Vesico-Vaginal Fistula in Murtala Mohammed Specialist Hospital, Kano." *Annals of African Medicine* 2 (2): 54–57.

- Kristof, N. 2009. "New Life for the Pariahs." *The New York Times*, October 31. Accessed 3 August 2015. http://www.nytimes.com/2009/11/01/opinion/01kristof.html?_r=0.
- Kristof, N. 2005. "The Illiterate Surgeon." *The New York Times*, June 12. Accessed 9 June 2016. http://www.nytimes.com/2005/06/12/opinion/the-illiterate-surgeon.html?_r=0
- Lancaster, R. 2011. *Sex Panic and the Punitive State*. Berkeley: University of California Press.
- Landry, E., V. Frajzyngier, J. Ruminjo, F. Asiimwe, T. Hamidou Barry, A. Bello, D. Danladi, et al. 2013. "Profiles and Experiences of Women Undergoing Genital Fistula Repair: Findings from Five Countries." *Global Public Health* 10: 1–17.
- Little, J. 2010. *Catherine's Gift: Stories of Hope from the Hospital by the River*. Oxford: Monarch.
- Malkki, L. 1996. "Speechless Emissaries: Refugees, Humanitarianism, and Dehistoricization." *Cultural Anthropology* 11 (3): 377–404.
- Mattingly, C., and L. Garro, eds. 2000. *Narrative and the Cultural Construction of Illness and Healing*. Berkeley: University of California Press.
- Maulet, N., M. Keita, and J. Macq. 2013. "Medico-Social Pathways of Obstetric Fistula Patients in Mali and Niger: An 18-Month Cohort Follow-up." *Tropical Medicine and International Health* 18(5): 524–533.
- Mosher, W. D., A. Chandra, and J. Jones. 2002. "Sexual Behavior and Selected Health Measures: Men and Women 15–44 Years of Age, United States, 2002". Advanced Data from Vital and Health Statistics No 362. Hyattsville, MD: National Center for Health Statistics.
- Mselle, L., K. M. Moland, B. E. Olsen, A. Mvungi, and T. Kohi. 2011. "‘I Am Nothing’: Experiences of Loss Among Women Suffering from Severe Birth Injuries in Tanzania." *BMC Women's Health* 11 (49): 1–12. doi:10.1186/1472-6874-11-49.
- Nguyen, V. 2010. *The Republic of Therapy: Triage and Sovereignty in West Africa's Time of AIDS*. Durham: Duke University Press.
- Operation Fistula. 2015. "About Fistula: A Brief Introduction to the Biggest Problem You've Never Heard of." <http://www.opfistula.org/fistula/>
- Phillips, B. S., D. N. Ononokpono, and N. W. Udofia. 2016. "Complicating Causality: Patient and Professional Perspectives on Obstetric Fistula in Nigeria." *Culture, Health and Sexuality* 18 (9): 996–1009. doi:10.1080/13691058.2016.1148198.
- Raassen, T. J., C. J. Ngongo, and M. M. Mahendeka. 2014. "Iatrogenic Genitourinary Fistula: An 18-Year Retrospective Review of 805 Injuries." *International Urogynecology Journal* 25 (12): 1699–706.
- République du Niger. 2011. *Plan de Développement Sanitaire (PDS) 2011-2015*. Ministre de la Santé Publique. Secrétariat General. Adopté en Conseil des Ministres le 27 Janvier 2011.
- Smith, M. O., and A. Bucher, dirs. 2007. *A Walk to Beautiful*. 85 min. New York: Engel Entertainment.
- United Nations. 1995. *Fact Sheet No. 23 on Harmful Traditional Practices Affecting the Health of Women and Children*. Geneva: United Nations.
- Vaughan, M. 1991. *Curing Their Ills: Colonial Power and African Illness*. Cambridge: Polity Press.
- Wall, L. L. 1998. "Dead Mothers and Injured Wives: The Social Context of Maternal Morbidity and Mortality Among the Hausa of Northern Nigeria." *Studies in Family Planning* 29 (4): 341–359.
- Winfrey, O. 2005. "Oprah Travels to Ethiopia's Fistula Hospital." *The Oprah Winfrey Show*, December 1.
- Winsor, M. 2013. "A Fate Worse than Death for Scores of African Women." *CNN online*, May 23. Accessed 3 August 2015. <http://www.cnn.com/2013/05/23/health/end-obstetric-fistula-day>.
- Zoller Seitz, M. 2008. "Healing Cultural Wounds." *The New York Times*, February 8. Accessed 10 August 2015. <http://www.nytimes.com/2008/02/08/movies/08walk.html>.