

Bedside manner and the invisible patient

The silence surrounding women's gynaecological health in Niger

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1. Obstetric fistula is caused by prolonged and obstructed labour, unrelieved by biomedical interventions such as caesarean section. The protracted pressure of the foetal head against a woman's pelvic tissues produces an abnormal pathway between her vagina and bladder and/or between her vagina and rectum, resulting in chronic incontinence of urine and/or faeces.

2. Foot drop commonly co-occurs with fistula (included in the 'obstructed labor injury complex' as described by Arrowsmith et al. 1996) and is thought to result from excessive compression of the sacral nerve plexus by the fetal head, causing permanent or temporary difficulty walking.

3. Women with fistula are typically from rural areas, resulting in very low educational attainment, often markedly lower than national averages (20 per cent [DHS 2006]). In Niger, among my sample of 100 women, only 11 per cent had any education at all, ranging between one and seven years of primary education. Landry et al. (2013) reported only 6.4 per cent primary or higher education attainment among women with fistula in Niger.

4. See Gordon & Paci (1997) on the concealment of cancer diagnoses in Tuscany, Italy; Bennett (1999) regarding the obfuscation of cancer diagnoses in northeast Thailand; Kaufert (1999) on disclosure practices among Aboriginal patients in Canada.

5. A contested number, contrasting with widely cited success rates which range between 75 to 90 per cent, but one which has been reported in some recent studies such as Maulet et al. (2013) which report a 37 per cent continence rate for their study in Mali and Niger, stressing that 'the quest for continence does not end with admission to a fistula center' (2013: 524). My own research has yielded a success rate (defined as continence following surgery and after three months) of 38 per cent. Such poor outcomes are not frequently reported.

In Niger, among individuals that value propriety, decorum, and 'respectful avoidance', discussions about bodies (even when they are working as they ought to be) are brief, circumspect, and sometimes conspicuously absent. Bodies, particularly female bodies, and the liquids they exude, their breasts and their genitals, are often seen as a source of shame and mystery. Anthropologists have long contended that the female body is thought to manifest polluting disruptions of the ideal (as it bleeds, births, lactates, miscarries, and swells) and thus is viewed as undisciplined and out of control, rendering women themselves as morally deficient and existentially disabled (see Douglas 1996; Buckley & Gottlieb 1988; Shildrick 1997; Manderson & Smith-Morris 2010). Unsurprisingly, such corporeal sources of shame are shrouded in silence.

During my year of fieldwork investigating the experience of obstetric fistula in Niger, women chuckled as they recalled their first periods, remembering their fear of the blood that trickled down their thighs, assuming that something had seriously and maybe fatally gone wrong. Women remembered how as girls of 13 or 14, they were married to men without a clear idea of where babies came from, or what happened between married couples. One woman shook her head and smiled, 'It was certainly a surprise!'

This silence is thicker when bodies break down, tear, or defy the norm. Indeed, not all female bodies are seen equally, as race, ethnicity, and disability further distance bodies from the male and abled norm. When women experience an obstetric complication that causes obstetric fistula,¹ a childbirth injury resulting in chronic incontinence, they are sent home from clinics only to discover that their bodies do not recover as expected. They are left leaking, and often unable to walk or even stand up due to foot drop (an injury caused by extreme nerve damage to the lower limbs due to the prolonged labour).²

Their feet don't work anymore. They are incontinent. And they don't know why.

'I had no idea a sickness like this one could exist'

In speaking with women, I heard again and again: 'I thought I was the only one in the world with this sickness'. Or, 'I believed that I was being punished by God'; 'I had no idea a sickness like this one could exist'; 'I believed a spirit had attacked my body'. Of the 100 women with fistula who I interviewed, only 10 had heard of fistula, or anything like it, before experiencing it first-hand.

I found that women's stories often followed a familiar narrative: following a prolonged and complicated labour lasting up to a week and frequently resulting in an emergency caesarean section, a woman wakes up in an unfamiliar hospital bed, sodden in a puddle of her own urine. She is told that it is normal, or that it will stop on its own, or maybe she is told nothing – just to go home. When she wraps up her forty days of post-partum rituals and begins to find her strength, she finds that the mysterious leak remains unrelenting.

And so begins the long and often unrewarding search for treatment, as women move between clinics and hospitals just as fluidly as between traditional healers and religious leaders, exhausting their financial resources but receiving few answers. Women go to health clinics where, if they are lucky, they will be told that they have a complication from labour, but more often than not they are told nothing. Perhaps they are referred on to another clinic or hospital, or perhaps they are sent away with no information – with

a shrug, maybe a box of unexplained (and often expired) pills, but several dollars poorer.

The women who make it past this first barrier (and many do not, abandoning the search for treatment for years or even decades) then enter a world of clinical negotiations and uncertainty. They are sent from one centre to the next, inefficiently pinballing through the system – frequently passing through half a dozen to a dozen clinics without being given a diagnosis.

'He didn't tell me anything'

'After you realized that you were leaking, when you went to see the doctor, what did he say?' I ask one woman. 'Nothing. He gave me a paper and told me to go to Niamey', she tells me. 'He said that I could be cured in Niamey'. 'He didn't explain what you had or what caused it?' I question further. 'No, he didn't tell me anything about that', she says, 'not a single thing'.

After months or sometimes several years of searching, women show up to fistula clinics with a large stack of loose and crumpled papers – old tests and referrals and some diagnoses scribbled in a language they don't speak and in an alphabet they can't read.³ 'Vesico-Vaginal fistula with partial urethral involvement', 'Large recto-vaginal fistula', 'VVF with circumferential defect'. But, despite the papers they clutch, for most of these women, when they finally make it to a fistula clinic, they've never even heard the word 'fistula' (or any of its local language translations) before.

Is it an unspoken policy of paternalistic beneficence? A protection of sorts? Is it because clinicians are overworked and underpaid? That centres are understaffed? That women are ashamed to speak about their leaky bodies, as often are local staff? That overburdened local surgeons (and undersupplied local centres) often rely on non-profit organizations to fund surgeries by foreign doctors who share no common language with the women? That these international surgical teams fly in for a few whirlwind days a year, technocrats efficiently anaesthetizing women within minutes of meeting them, maximizing productivity while minimizing time spent with women off the table?

Or is the problem one of information retention? If a woman was told somewhere along the line that she had 'vesico-vaginal fistula with partial urethral involvement' without any explanation, with no drawings, with no teaching, I can imagine that she might not fully digest the information. In the face of language, class, ethnic, and educational disparities between practitioners and patients, the reticence of patients to ask for clarification is visible across numerous cultures and contexts.

Still, after observing countless hours of interactions between clinicians and patients at fistula centres and maternity clinics, I doubt that women are given much to ruminate on at all. 'Just tell them to wait', a harried local clinician instructed me after my supplication that more information be passed on to the women who weren't chosen for surgery. 'They don't need to know any more than that'. Don't explain the particularities; don't explain the timelines; don't explain the risks; don't explain the contingencies.

Such withholding of information by practitioners is a globally noted phenomenon, most commonly evidenced in relation to cancer, where non-disclosure is often deemed more ethical than delivering a death sentence in places with little more to offer for treatment than palliative care.⁴

(From left to right, above to below)
Fig. 1. Midwives taking a break at Niger's largest maternity hospital.
Fig. 2. Portrait of a Hausa woman, Maradi, Niger.
Fig. 3. Portrait of a Kanuri woman, Niamey, Niger.
Fig. 4. Portrait of a Songhai woman, Niamey, Niger.
Fig. 5. Portrait of a Tuareg woman, Niamey, Niger.



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Yet, 'paternalistic beneficence' fails to fully explain communication deficits between practitioners and obstetric fistula patients in Niger.

A study in Turkey found that practitioners were more likely to inform patients of their diagnosis as the patient's socio-economic status and education level increased (Buken 2003). According to Al-Amri (2013), in Saudi Arabia, women are far less likely to receive information about their condition than are men, due to expectations regarding women's subservience to male kin and their diminished autonomy. Thus, non-disclosure becomes not only about the ethics of protection, or the realities of overburdened healthcare systems, but a manifestation of unequal power relationships between practitioners and patients, moored to the politics of gender and class.

'Sometimes we forget to tell her'

I've spoken with women who stay up nights worrying about why they haven't had their period since the catastrophic complication which caused their fistula, wondering if they will ever be able to conceive. 'During the c-section, did they take out your uterus?' I ask a young Hausa woman with fistula. 'I don't know. Sometimes I worry that they did. But no one told me. I just don't know'. After a quick glance at a chart or a word exchanged with a clinician, I find the information many women have been seeking for years. Too frequently, I find that indeed, she no longer has a uterus. It was removed during an emergency caesarean section due to rupture or irreversible damage. She was never consulted. She was never asked. After everything was said and done, she wasn't even told. So, every month she waits for a period that isn't coming. She waits for a pregnancy that never will be.

'Sometimes we forget to tell her', a Nigerien obstetrician conceded. 'We are so busy here. Other times we tell her family, but there is so much shame. So, we say "the uterus was turned" rather than "the uterus was removed"'. I don't know if they know what that implies. A hysterectomy is a difficult thing to talk about'.

Women with fertility problems, large fibroids, ovarian tumours, severe genital tract infections, or ambiguous genitalia seem to also find their way to fistula centres. Sometimes because they are leaking, and other times because reproductive or genital abnormalities were treated by village surgeons, or barbers, (know as *wanzami*) who haphazardly hacked at a woman's genitals – leaving her with her original problem unaddressed, but also with fistula.

For example, three women in my sample were treated in their communities by *wanzami* for '*dan guriya* (literally, 'little cotton seed'), a local illness category which encompasses both abnormal genitals (vaginas thought to have closed shut by the growth of diseased flesh), and abnormal sexual behaviours (namely the disinterest in men and sexual refusal following marriage). In order to restore reproductive normalcy, flesh is removed from these young women's vaginas, sometimes resulting in unintentional damage to continence mechanisms and causing fistula. After an examination, these women are often excluded from the list of surgical priority – their problems are too big, too complex, or too unrelated to be treated. But none of this information is transferred to the woman. As each surgical team passes through, and as the months pass by, she cries at night and wonders why she is always waiting and never called. She doesn't know why her body is different. She is never told why she wasn't chosen.

* * *

Whatever their particular case, the vast majority of women with whom I spoke did not know what they had, what caused it, how to manage it, what medicines they

were taking, what their chances were of cure or continence, or when they could expect to return home. They were told to be patient and to wait. So they were, and they did.

Some might make the argument that it doesn't really matter how much information the woman has about her condition. For women with fistula, they might (rightly) argue that she probably isn't interested in whether her fistula is high or low, large or small, or if it involves her urethra. She's interested in whether she's dry or not.

But the silence isn't without consequence. One woman who had been waiting at a clinic for over a year and still had not even been consulted by a doctor lamented: 'Since I've been here, my life has gone by. My sisters and my cousins have given birth, some have married – but I wasn't there. I missed it all because I was here, waiting'. For many, prolonged absences result in anxiety and weakened social networks as women become increasingly peripheral to their social lives back home. As one woman told me, 'If I knew that there was no hope, I'd go home. But they haven't told me that I won't be cured, so I will wait for the next operation'.

As many fistula centres in Niger have tremendously long backlogs, but also perform few and infrequent reparative surgeries, the women with fistula I interviewed had stayed an average of five months at their respective clinics, and as long as 28 months without having received an operation. And when women did finally receive surgeries, their quest for continence was frequently far from over. Of the 100 women with fistula I interviewed, 44 per cent had already undergone three or more previous unsuccessful surgeries at the time of the interview (and some as many as 11 previous failed surgeries).

Many of these women will never achieve continence, but must live with fistula as a chronic condition. However, women are not taught strategies (nor given appropriate technologies such as urethral plugs) to manage chronic fistula. Their slim chances for surgical success are never communicated. So women spend years of their lives removed from their families, waiting for the next surgery (without the knowledge that each failed surgery diminishes the chances that the next intervention will succeed).

Fistula is billed as a highly curable, acute condition, easily remedied through surgical intervention. However, with surgical success rates for fistula that hover around 40 per cent,⁵ (and are much lower for certain types of fistula than for others), a woman cannot make an informed decision about her treatment if she doesn't understand what she's dealing with. She cannot decide if continuing to seek (biomedical) care – a lengthy, and often lonely, quest that removes her from her family, friends, and normalcy – is worth it. This decision should not be made for her. But everyday, with every empty consultation, it is.

The first step to 'empowering' women isn't sewing them up; it is giving them a sense of control over their circumstances, improving their comprehension of their condition. It is explaining the mechanics of their own bodies, diminishing the mystery, and thus taking the power away from the clinicians, the clinic, the traditional healers, or the spirit world. Women's abilities to understand their bodies, and to make decisions as to what's best for themselves based on accurate information regarding their chances for cure, is woefully underestimated. To bank on old platitudes, information is power, and it ought to be shared. ●



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(From left to right, above to below)

Fig. 6. Women waiting to be seen, Danja, Niger.

Fig. 7. A young Tuareg woman and her father wait on hospital grounds.

Fig. 8. A woman with fistula publicly offering thanks to a non-profit organization for the donation of soap, fabric, perfume, and rice.

Fig. 9. A midwife looking over a woman's file at a clinic, Niamey.

Fig. 10. A woman with fistula clutches her health files, acquired over two decades of living with the condition.

Fig. 11. A woman with fistula during afternoon prayer.

Fig. 12. Woman with fistula, beading bracelets to pass the time.