Demographic profile and treatment outcomes of 100 women with obstetric fistula in Niger

Alison Heller, Ph.D.[1]

Keywords: Niger, obstetric fistula, West Africa, stigma

Abstract:

Introduction: Due to high fertility rates, low access to emergency obstetric care, and the poor quality of that care, obstetric fistula is relatively widespread in Niger.

Methods: Mixed-methods research was carried out over a total of eighteen months with 100 women with fistula at four fistula centers in Niger, three in the capital of Niamey and outside the city of Maradi.

Results: The one hundred women who made up the research sample reflect marked diversity in ethnicity, age, marital situation, parity, length of time living with fistula, and surgical history and outcomes. At the time of initial interviews women ranged from 15-70 years old (average 31.0±10.6), but had developed fistula from 13-54 years old (average 23.4 ±8.4). Women had lived with fistula between 1 month to 50 years (average 6.7 years ±8.6). At initial interview, women waited an average of 5.8 months (±9.9) while living at fistula centers, ranging from 2 weeks to 6 years. At the end of the research period, only 22 of the 61 women who underwent surgeries during the research period (36%) attained continence. The remaining 39 women (64%) were still incontinent.

Conclusions: Women with fistula in Niger's clinics are more demographically diverse than commonly portrayed. Additionally, it was more difficult for women to access surgical repair and that repair was less successful than women themselves anticipated. Notably, the quality of care varied considerably between the four fistula centers. Long waits combined with poor surgical outcomes often resulted in negative social outcomes for women.

[1]*University of Maryland College Park, Department of Anthropology, College Park, MD*

Introduction

Obstetric fistula, a maternal childbirth injury that results in chronic incontinence, affects an estimated 1 to 3.5 million women in resource-poor countries.[1,2] Obstetric fistula is caused by prolonged, obstructed labor unrelieved by medical intervention such as cesarean section. The protracted pressure of the fetal head against a woman's pelvic tissues produces an ischemic injury that leads to fistula formation between the vagina and bladder and/or between the vagina and rectum, resulting in chronic incontinence of urine and/or feces. There has been no need for a specialized fistula hospital

Please cite this paper as: Heller A. Demographic profile and treatment outcomes of 100 women with obstetric fistula in Niger. Proc Obstet Gynecol. 2017;7(2): Article 1 [15 p.]. Available from: http://ir.uiowa.edu/pog/ Free full text article.

Corresponding author: *Alison Heller, Ph.D., University of Maryland College Park, Department of Anthropology, 1111 Woods Hall, 4302 Chapel Drive, College Park, MD 20742, (301) 405-1423, aheller@umd.edu*

Financial Disclosure*: The author received a small research grant from Worldwide Fistula Fund in 2012.*

in the United States for over 100 years. Yet, due to high fertility rates, low access to emergency obstetric care, and the generally-poor quality of that care, obstetric fistula is relatively widespread in much of sub-Saharan Africa, particularly in the West African country of Niger. Niger has the world's highest total fertility rate of 7.6 births per woman[3] and is ranked by the United Nations Development Programme 188/188, situating it as the least developed country in the world.[4] This confluence of pronatalism and poverty results in predictably poor maternal health outcomes.

In Niger, 1 in 23 women are expected to die in their lifetimes from pregnancy-related causes.[5] For every woman who dies from obstetric complications in Niger, approximately ten more suffer from severe acute maternal morbidity.[6] Obstructed labor, the cause of obstetric fistula, is the leading cause of maternal morbidity in Niger.[6] Although there are few reliable estimates, Niger is believed to have one of the highest rates of obstetric fistula incidence in the world, between 700 and 800 new cases per year.[7,8] Although historically inaccessible to women, fistula repair surgeries are becoming more accessible in much of Niger and throughout sub-Saharan Africa due to a relatively recent increase in international attention, interest, and funding.

This article examines the demographic and ethnic profile of 100 women seeking treatment at four fistula centers in rural and urban Niger. Specifically, the findings related to women's reproductive and marital histories, as well as their clinical experiences, are analyzed. Women in Niger have similar demographics with respect to their lack of formalized education, rural residence, and poverty. However, women with fistula in Niger are also diverse in their age, parity, marital status, and their experiences living with fistula. Women seeking treatment for their fistulas in Niger generally have poor surgical outcomes and experience long wait-times at fistula centers. There is, however, a marked diversity in the quality of care between fistula centers in Niger.

Materials & Methods

This fieldwork was carried out over the course of one year (2013) plus two additional summers (2011, 2014) at four fistula centers. Three centers were located in Niger's capital of Niamey (*l'Hôpital National de Lamordé, Centre National de Reference des Fistules Obstétricale [CNRFO],* and *Dimol)*, and one was located about 500 miles east of the capital in a rural area approximately 20 miles north of the Nigerian border (the *Danja Fistula Center*). Two centers were state-run (Lamordé and CNRFO) and two were privately-funded and run (Danja and Dimol).

This study adopted a mixed-methods approach to data collection. Information was gathered on marital and reproductive histories as well as fistula and treatment-seeking experiences. Quantitative data were captured through multiple standardized surveys. These included a comprehensive demographic survey and a modified version of the HIV/AIDS Stigma Instrument, or HASI-P, used to measure fistula-related social stigma.[9] Qualitative data were captured through a breadth of standard ethnographic methodologies including participant observation, focus groups, and most-importantly, in-depth

interviews with one hundred women with fistula as well as with thirty-eight family members, husbands, and fistula professionals.

Although attempts were made to include a diverse range of experiences, the sample was not universal. Women were purposively sampled based on a range of factors including linguistic abilities, familiarity and comfort with researcher, and desire to participate. Clinical diagnosis was not an inclusion criterion (as Dimol did not have access to qualified specialists), neither was age nor nationality. Family members, husbands, and fistula professionals were purposively sampled based on a range of factors including linguistic ability, desire to participate, access (for family members, distance from home to fistula center), and specialized knowledge (for experts).

Interviews and surveys were conducted after comprehensive informed oral consent. This study was approved by 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. All interviews were conducted in Hausa, Zarma, or French by the author/researcher (all Zarma and some Hausa interviews were facilitated by a research assistant for translation). Although Tuareg, Fulani, Kanuri, and Mossinke women were also included in the research, they were multi-lingual in either Hausa or Zarma.

Women's surgical outcomes were limited to self-reported experiences of continence (as defined by the ability to hold urine without the use of any external apparatus or technology) and did not include clinical diagnoses. As most people in rural Niger do not prioritize tracking their or their children's ages, many do not report them accurately or consistently. When inconsistencies arose, ages were triangulated.

Interviews were voice recorded and surveys were collected using paper forms and recorded and stored in a Microsoft Excel database. Textual data such as interview notes and field notes were transcribed, systematically coded, and analyzed using the qualitative analysis software package MAXQDA.

Results

The one hundred women in the study are relatively homogeneous in educational attainment, rural residence, and religion. All of the women identified as Muslim, and all but three came from rural villages. However, these women also reflect marked diversity in ethnicity, age, marital situation, parity, length of time living with fistula, and surgical history and outcomes. The 100 women sampled represented six ethnic groups, and all results are reported by ethnic identification.

Compared to many West African countries, Niger is relatively ethnically homogenous, composed of only seven main ethnic groups. According to the 2010 Nigerien Government census, the largest ethnic group in Niger is the Hausa, constituting more than half (56%) of Niger's population, followed by the Zarma, or the closely associated ethnic group, the Songhai (21% of the population). Both the Hausa and Zarma are sedentary farmers, living primarily in the arable southern tier of Niger

(although the Zarma live predominantly in the west of the country while the Hausa regions are found in the central and east of Niger). The remainder of Nigerien people are nomadic, semi-nomadic, or historically nomadic pastoralists, including the Tuareg (primarily found in the north of Niger) constituting 9% of Niger's population, the Fulani (dispersed throughout the country) who compose 9% of the population, the Kanuri (found in the far east of the country) who constitute 5%, and the Toubou and Diffa Arabs (as well as other small minority groups) who together make up about 1% of Niger's remaining population.

Of the 100 women with fistula included in this study, 41 were Hausa, 31 were Zarma or Songhai, 14 were Tuareg, 8 were Fulani, 5 Kanuri, and 1 was Mossinke from Mali. Although women's ethnic identities were not considered in developing the research sample, the research sample is fairly representative of the population. Hausa women were slightly under-represented and Zarma women slightly over-represented in the sample as three of the four fistula centers were located in the capital of Niamey, which is Zarma territory. Although women come to the capital from all over the country to seek care, Hausa women in the east and central regions of the country often first seek treatment in regional hospitals or in Nigeria or Chad. For example, in the sample from Danja, located in Hausa territory, 92% of the women identified as Hausa (compared to CNRFO/Lamordé in the capital, where only 18% of the women identified as Hausa).

Table 1 shows the basic demographic characteristics of the 100 women in the sample. At the time of initial interview, women ranged from 15-70 years old, with an average age of 31.0 (±10.6). The majority of women (64%) were between 20-35 years old. Women had an average of 0.5 (±1.6) years of education. On average, 89% of the sample had no formal education, which is representative of Nigerien women as a whole, 80% of whom have had no formal education, increasing to 88% among rural women.[3] Unsurprisingly, in the sample, Zarma women tended to be the best educated (with 7 women having primary or secondary education), as they live closest to higher resourced areas near the capital of Niamey, while the Tuareg, Mossinke, and Kanuri – who tend to live in the most remote regions of the country – had no formalized education. Although a couple of women could recognize Arabic suras, none of the women in the sample was literate nor could any speak more than a few words of French, the official language of the country.

Women married between the ages of 10-23 years old (average 15.5 ±2.5), with notable differences by ethnic group. Mossinke and Kanuris averaged 13.8 years (±1.2) at age of first marriage while Tuaregs averaged 17.0 years (±2.0). The sample average of 15.5 years old is just under the national average of 15.7 years old (which dips to 15.5 among the poorest quintile of the population, and to 15.6 among women with no education).[3]

Table 1. Demographic characteristics by Ethnic group of 100 women with fistula

	Hausa	Zarma	Tuareg	Fulani	Other*	Total**
Characteristic	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Number of women	41 (41)	31 (31)	14 (14)	8 (8)	6 (6)	100 (100)
Age at time of interview						
12-19 years	5 (12.2)	3 (9.7)	1 (7.1)	0 (0.0)	0 (0.0)	9 (9.0)
20-27 years	11 (26.8)	10 (32.3)	6 (42.9)	4 (50.0)	5 (83.3)	36 (36.0)
28-35 years	12 (29.3)	12 (38.7)	4 (28.6)	0 (0.0)	0 (0.0)	28 (28.0)
36-43 years	5 (12.2)	4 (12.9)	2 (14.3)	0 (0.0)	1 (16.7)	12 (12.0)
44+	8 (19.5)	2 (6.5)	1 (7.1)	4 (50.0)	0 (0.0)	15 (15.0)
Average age at time of interview	31.7 (±12)	29.3 (±7.3)	30.5 (±13.1)	35.2 (±14.3)	26.3 (±7.8)	31.0 (±10.6)
Education						
No education	36 (92.3)	24 (77.4)	14 (100.0)	7 (87.5)	6 (100.0)	87 (88.8)
Primary	2 (5.1)	6 (19.4)	0 (0.0)	1 (12.5)	0 (0.0)	9 (9.2)
Secondary	1 (2.6)	1 (3.2)	0 (0.0)	0 (0.0)	0 (0.0)	2 (2.0)
Average years of education	*0.4 (±1.6)*	*1.0 (±2)*	*0 (±0)*	*0.2 (±0.6)*	*0 (±0)*	*0.5 (±1.6)*
Age at first marriage						
10-13 years	12 (31.6)	3 (9.7)	0 (0.0)	2 (25.0)	3 (50.0)	20 (20.6)
14-17 years	19 (50.0)	22 (71.0)	9 (64.3)	6 (75.0)	3 (50.0)	59 (60.8)
18-21 years	7 (18.4)	5 (6.5)	5 (35.7)	0 (0.0)	0 (0.0)	17 (17.5)
22- 25 years	0 (0.0)	1 (3.2)	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.0)
Average age at first marriage	*14.9 (±2.7)*	*16 (±2.5)*	*17.0 (±2.0)*	*15.0 (±1.2)*	*13.8 (±1.2)*	*15.5 (±2.5)*
Marital status at initial interview						
Married	14 (34.1)	12 (38.7)	10 (71.4)	2 (25.0)	0 (0.0)	38 (38.0)
Divorced	11 (26.8)	5 (16.1)	1 (7.1)	2 (25.0)	4 (66.7)	23 (23.0)
Separated	15 (36.6)	14 (45.2)	1 (7.1)	4 (50.0)	2 (33.3)	36 (36.0)
Widowed	1 (2.4)	0 (0.0)	2 (14.3)	0 (0.0)	0 (0.0)	3 (3.0)

*Including the Mossinke and Kanuri ethnic groups. **Some totals do not add up to 100 or 100% due to rounding or missing data.

By ethnic group, Hausa women in the sample were married slightly younger than the national average by region (15.3 in the Maradi and Zinder regions from which most Hausa women came), and 32% were married by 10-13 years old. Zarma and Tuareg women were fairly representative of their regions (16.1 in the Tillaberi region where most Zarma women lived and 17.1 in the northern Agadez region from which most Tuareg women came).[3] At the time

of initial interview, the largest proportion of women (38%) remained married, followed closely (36%) by women in a liminal state of marital separation. Only 23% of women were divorced and 3% were widowed. Although the sample size is smaller, Tuareg women demonstrated a greater marital resilience in the face of fistula, as 71% remained married and only 14% were divorced or separated.

Table 2. Reproductive history and health characteristics of 100 women with fistula by ethnicity

	Hausa	Zarma	Tuareg	Fulani	Other	Total*
Characteristic	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Number of women	41 (41.0)	31 (31.0)	14 (14.0)	8 (8.0)	6 (6.0)	100 (100.0)
Age at first birth						
12-15 years	10 (27.8)	3 (9.7)	1 (7.1)	0 (0.0)	3 (50.0)	17 (17.9)
16-19 years	21 (58.3)	19 (61.3)	8 (57.1)	8 (100.0)	3 (50.0)	59 (62.1)
20-23 years	5 (13.9)	7 (22.6)	5 (35.7)	0 (0.0)	0 (0.0)	17 (17.9)
24-27 years	0 (0.0)	2 (6.5)	0 (0.0)	0 (0.0)	0 (0.0)	2 (2.1)
Average age at first birth	*17.0 (±2.3)*	*18.5 (±2.6)*	*18.4 (±1.8)*	*17.1 (±1.1)*	*15.7 (±1.4)*	*17.6 (±2.4)*
Number of total pregnancies						
0	2 (4.9)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	2 (2.1)
1	9 (22.0)	12 (40.0)	5 (35.7)	3 (37.5)	4 (80.0)	33 (34.0)
2 to 4	10 (24.4)	8 (26.7)	5 (35.7)	4 (50.0)	1 (20.0)	28 (28.9)
5 to 7	10 (24.4)	9 (30.0)	3 (21.4)	0 (0.0)	0 (0.0)	22 (22.7)
8 +	10 (24.4)	1 (3.3)	1 (7.1)	1 (12.5)	0 (0.0)	13 (13.4)
Average number of pregnancies	*4.7 (±3.4)*	*3.2 (±2.4)*	*3.3 (±2.5)*	*2.9 (±2.3)*	*1.5 (±0.8)*	*3.7 (±2.9)*
Number of living children						
0	22 (53.7)	16 (51.6)	4 (28.6)	6 (75.0)	6 (100.0)	54 (54.0)
1	9 (22.0)	5 (16.1)	3 (21.4)	0 (0.0)	0 (0.0)	17 (17.0)
2	2 (4.9)	3 (9.7)	5 (35.7)	1 (12.5)	0 (0.0)	11 (11.0)
3 or 4	6 (14.7)	5 (16.1)	0 (0.0)	1 (12.5)	0 (0.0)	12 (12.0)
5+	2 (4.9)	2 (6.5)	2 (14.3)	0 (0.0)	0 (0.0)	6 (6.0)
Average number of living children	*1.1 (±1.6)*	*1.2 (±1.6)*	*1.7 (±2)*	*0.6 (±1.2)*	*0.0 (±0)*	*1.1 (±1.6)*

*Some totals do not add up to 100 or 100% due to rounding or missing data.

Table 2 shows the reproductive history and health characteristics of the women

in the sample. Women waited an average of 2.1 years between their first marriage and first birth, with a first birth at an average of 17.6 years (±2.4) (a year less than the national average, 18.6).[3] Average ages of first births ranged from 15.7 (±1.4) among Kanuri and Mossinke to 18.5 (±2.6) among the Zarma. Ranging from 0 to 12, at the time of interview, women had an average of 3.7 (±2.9) pregnancies. Kanuri and Mossinke women had the lowest average pregnancies of 1.5 (±0.8) while Hausa women had the highest of 4.7 (±3.4). Although 35% of the sample had 5 or more pregnancies, only 6% had 5 or more living children. The average number of living children was 1.1 (±1.6), lowest among Kanuri and Mossinke women at 0 children and highest among Tuareg women at 1.7 (±2.0) children.

Table 3. Fistula history characteristics of 100 women with fistula by ethnicity

	Hausa	**Zarma**	**Tuareg**	**Fulani**	**Other**	**Total***
Characteristic	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Number of women	41 (41.0)	31 (31.0)	14 (14.0)	8 (8.0)	6 (6.0)	100 (100.0)
Duration of labor leading to fistula						
<24 hours	4 (10.2)	2 (6.7)	0 (0.0)	0 (0.0)	0 (0.0)	6 (6.2)
1-2days	14 (35.9)	13 (43.3)	2 (14.3)	3 (37.5)	4 (66.7)	36 (37.1)
3-4days	17 (43.6)	10 (33.3)	8 (57.1)	3 (37.5)	0 (0.0)	38 (39.2)
5+days	4 (10.2)	5 (16.7)	4 (28.6)	2 (25.0)	2 (33.3)	17 (17.5)
Average duration of labor leading to fistula	2.7 (±1.6)	2.9 (±2)	4.0 (±2.1)	2.9 (±1.8)	3.1 (±2.4)	3.0 (±1.9)
Age at fistula onset						
< 20 years	16 (39.0)	13 (41.9)	8 (57.1)	4 (50.0)	5 (83.3)	46 (46.0)
20-29 years	11 (26.8)	12 (38.7)	4 (28.6)	2 (25.0)	1 (16.7)	30 (30.0)
30-39 years	10 (24.4)	6 (19.4)	2 (14.3)	1 (12.5)	0 (0.0)	19 (19.0)
> 39 years	4 (9.8)	0 (0.0)	0 (0.0)	1 (12.5)	0 (0.0)	5 (5.0)
Average age at fistula onset	*25.5 (±10)*	*22.6 (±6.5)*	*20.6(±5.8)***	*25.0 (±10)*	*17.0 (±2.4)*	*23.4 (±8.4)*
Time living with fistula						
< 7 months	4 (9.8)	7 (22.6)	2 (14.3)	0 (0.0)	0 (0.0)	13 (13.0)
7-23 months	8 (19.5)	5 (16.1)	2 (14.3)	1 (12.5)	1 (16.7)	17 (17.0)
2-6 years	18 (43.9)	10 (32.3)	8 (57.1)	3 (37.5)	2 (33.3)	41 (41.0)
> 6 years	11 (26.8)	9 (29.0)	2 (14.3)	4 (50.0)	3 (50.0)	29 (29.0)
Average years living with fistula	*6.8 (±8.4)*	*5.0 (±6.5)*	*7.1 (±3.4)*	*10.3 (±8.8)*	*7.9 (±9.1)*	*6.7 (±8.6)*

*Some totals do not add up to 100 or 100% due to rounding or missing data. **Including two cases of recidivistic fistula, the average age increases to 21.5 (± 6.1)

Table 3 demonstrates women's history with fistula onset and the length of time living with fistula. The duration of the labor leading to fistula ranged between 5 hours and 9 days, averaging 3.0 days (±1.9). Average labor times were the shortest for the Zarma [2.7 (±1.6)] who tend to live closest to the capital and thus to quality emergency obstetric care, and the longest for the Tuareg [4.0 (±2.1)] who tend to live in the northern desert, furthest from health care. Women developed fistula between 13-54 years old (average 23.4 ±8.4), and throughout their reproductive life spans, with fistulas occurring from their first to twelfth labors. Forty-six percent of women developed fistula under the age of 20, and 55 women were primiparous at the time of fistula development. At the time of initial interview, women had lived with fistula for an average of 6.7 years (±8.6), ranging from 1 month to 50 years. Twenty-nine percent of women lived with fistula for more than six years. Zarma women, who tend to live closest to care, lived with fistula for an average of 5.0 years (±6.5), half that of the nomad-pastoralist group the Fulani who averaged 10.3 years (±8.8) living with the injury.

Table 4 shows women's surgical histories and outcomes. Eighty-six women of the 100 women in the sample were actively seeking surgery for their fistulas during the research period. Of the fourteen women not actively pursuing surgeries, 9 came to centers for other reasons (either with other health complaints, for prophylactic cesarean sections for subsequent pregnancies, or for trainings), 3 women were categorized as incurable (and thus not operated on), and 2 women were treated with catheters. Of the 86 women pursuing fistula repair surgeries, only 61 underwent operations. The remaining 25 women did not receive surgeries during the research period due to long wait times, infrequent surgeries, and the preference of surgeons to operate first on more straightforward or simple cases. Nine women returned home without receiving surgeries, one woman died of unknown causes while waiting at a center, and the remaining fifteen continued to wait at centers at the end of the research period. At the time of initial interview, women had waited an average of 5.8 months (±9.9) while living at fistula centers, ranging from 2 weeks to 6 years. At the end of the research period, only 22 of the 61 women who underwent surgeries during the research period (36%) attained continence. The remaining 39 women (64%) remained incontinent. At the conclusion of the study, the 100 women had undergone a combined life-long total of 278 fistula repair surgeries, ranging from 0 to 11 previous surgeries each. While 39% of women underwent 0 or 1 cumulative surgeries, 33% underwent 4 or more.

Surgical success, and women's ability to secure surgeries, varied substantially by center, as demonstrated by Table 5. Danja provided both the most reliable path to surgery and more promising surgical outcomes for women. Ninety-six percent of women at Danja seeking surgery were operated on during the research period, with women waiting an average of only 1.9 (±1.0) months. Forty-one percent of women operated at Danja achieved continence, while 59% did not. At CNRFO/Lamordé, women had waited an average of 5.0 (±5.4) months. Only two-thirds of women

seeking surgery underwent operations during the research period, 31% of whom achieved continence (while 69% did not). Women at Dimol had the least success in securing an operation (less than half, 47%, of women seeking surgeries were operated on during the research period). They had waited, on average, the longest period of time—11.6 (±19.0) months.

Table 4. Surgical history and outcomes of 100 women with fistula by ethnic grouping

	Hausa	Zarma	Tuareg	Fulani	Other	Total*
Characteristic	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Number of women	41 (41.0)	31 (31.0)	14 (14.0)	8 (8.0)	6 (6.0)	100 (100.0)
Number of women looking for surgery	37 (90.2)	29 (93.5)	9 (64.3)	6 (75.0)	5 (83.3)	86 (86.0)
Number of women who underwent surgery	28 (68.3)	19 (61.3)	8 (57.1)	2 (25.0)	4 (66.7)	61 (61.0)
Number of previous fistula surgeries						
0 or 1	14 (34.1)	14 (45.2)	7 (50.0)	2 (25.0)	2 (33.3)	39 (39.0)
2 or 3	17 (41.5)	6 (19.4)	3 (21.4)	1 (12.5)	1 (16.7)	28 (28.0)
4 or 5	8 (19.5)	6 (19.4)	1 (7.1)	3 (37.5)	2 (33.3)	20 (20.0)
6+	2 (4.9)	5 (16.1)	3 (21.4)	2 (25.0)	1 (16.7)	13 (13.0)
Average no. of previous fistula surgeries	*2.7 (±2.5)*	*3.5 (±2.1)*	*2.2 (±2)*	*4.4 (±2.9)*	*3.3 (±2.7)*	*2.8 (±2.2)*
Time waiting at clinic at initial interview						
< 1 month	6 (20.7)	5 (17.9)	3 (30.0)	2 (33.3)	0 (0.0)	16 (20.5)**
1-2 months	6 (20.7)	4 (14.3)	3 (30.0)	1 (16.7)	0 (0.0)	14 (17.9)
3-6 months	11 (37.9)	12 (42.9)	1 (10.0)	3 (50.0)	2 (40.0)	29 (37.2)
7-12 months	5 (17.2)	5 (17.9)	3 (30.0)	0 (0.0)	1 (20.0)	14 (17.9)
>12 months	1 (3.4)	2 (7.1)	0 (0.0)	0 (0.0)	2 (40.0)	5 (6.4)
Average months waiting at clinic	*4.5 (±6.8)*	*5.3 (±5.5)*	*3.9 (±4.2)*	*2.6 (±2.4)*	*23.6 (±29.8)*	*5.8 (±9.9)*
Surgical outcome by continence						
Wet (incontinent)	16 (57.1)	12 (63.2)	5 (62.5)	2 (100.0)	4 (100.0)	39 (63.9)
Dry (continent)	12 (42.9)	7 (36.8)	3 (37.5)	0 (0.0)	0 (0.0)	22 (36.1)

*Some totals do not add up to 100 or 100% due to rounding or missing data. **Only the women who were looking for surgery were counted (n=86). Eight women could not estimate how long they had been at the center and so their data were left out of calculations, bringing the total to 78 women.

Table 5. Surgical history and outcomes of 100 women with fistula by fistula center

Characteristic	Danja Fistula Center *n* (%)	CNRFO/ Lamordé* *n* (%)	Dimol *n* (%)	Total *n* (%)
Hausa	23 (92.0)	9 (17.6)	9 (37.5)	41 (41.0)
Zarma	0 (0.0)	27 (52.9)	4 (16.7)	31 (31.0)
Tuareg	2 (8.0)	6 (11.8)	6 (25.0)	14 (14.0)
Fulani	0 (0.0)	6 (11.8)	2 (8.3)	8 (8.0)
Other	0 (0.0)	3 (5.9)	3 (12.5)	6 (6.0)
Number of women	25 (25.0)	51 (51.0)	24 (24.0)	100 (100.0)
Number of women looking for surgery	23 (92.0)	48 (94.1)	15 (62.5)	86 (86.0)
Number of women who underwent surgery	22 (88.0)	32 (62.7)	7 (29.2)**	61 (61.0)
Time waiting at clinic at initial interview				
< 1 month	3 (20.0)	10 (20.8)	3 (18.8)	16 (20.5)***
1-2 months	6 (40.0)	6 (12.5)	2 (12.5)	14 (17.9)
3-6 months	6 (40.0)	21 (43.8)	3 (18.8)	29 (37.2)
7-12 months	0 (0.0)	8 (16.7)	6 (37.5)	14 (17.9)
>12 months	0 (0.0)	3 (6.3)	2 (12.5)	5 (6.4)
Average months waiting at clinic	*1.9 (±1.0)*	*5.0 (±5.4)*	*11.6 (±19.0)*	*5.8 (±9.9)*
Surgical outcome by continence				
Wet (incontinent)	13 (59.0)	22 (68.8)	4 (57.1)	39 (63.9)
Dry (continent)	9 (41.0)	10 (31.2)	3 (42.9)	22 (36.1)

*The centers CNRFO and Lamordé were calculated together due to the movement of women between the two centers. **Dimol did not offer women surgeries, so these women were initially interviewed at Dimol, but underwent surgeries elsewhere, either at CNRFO or out of the country. ***Only the women who were looking for surgery were counted. Eight women could not estimate how long they had been at the center and so their data were left out of calculations.

Discussion

Beyond low levels of formal education, rural residence, high levels of poverty, and demographic characteristics in line with national trends such as ages in marriage and first birth, this study reveals a high level of diversity among the women who develop fistula in Niger. Although women with fistula are frequently portrayed in media and humanitarian accounts to be teenaged ([10,11] for example), this study demonstrates that more women with fistula were over the age of 44 than under the age of 20, with an average age of 31 years old at time of interview. This may be partially a reflection of the

particularly challenging fistula care context in Niger, where because of limited options for surgeries women remain at (or return to) centers for years and even decades. Although 46% of women developed fistula under the age of 20 years old, women developed fistula throughout their reproductive life spans, between 13-54 years old, (average 23.4), from their first to twelfth labors. Not only is this research important in revealing who women with fistula are, but it also reveals important information about how they seek treatment.

However, several methodological limitations of this study are acknowledged which may influence the findings. First, although attempts were made to include a diversity in age, ethnicity, and experience, the sample was not universal, random, nor representative. Second, as women's surgical outcomes were limited to self-reported experiences of continence, the study could not distinguish incontinence due to repair failure from residual incontinence despite fistula closure (nor could any conclusions about surgical success based on fistula complexity be made). Also, as wait times were recorded at initial interviews, women who had newly arrived to centers (but may have continued to wait at centers for months or even years) artificially decreased average wait times. Finally, women were not systematically followed back home in an attempt to measure degrees of social marginalization and social rupture. As such, women's accounts were subject to recall biases.

Nonetheless, this study uncovers the prolonged and tortuous care-seeking episodes that women with fistula endure. At the time of initial interview, 29% of women had lived with fistula for over six years, ranging from only a few weeks to 50 years, with averages spanning from 5 years among Zarma women to 10.3 years among Fulani women. Twenty-one women had lived with fistula for over a decade, 11 of whom had lived with fistula for over two. The number of women living with fistula for such notable lengths speaks to both issues of access to treatment and the quality of care in Niger. Poor access to high-quality medical intervention at the time of obstetric emergencies is widely acknowledged to be the main factor in Niger's (and much of sub-Saharan Africa's) continued incidence of fistula. Yet, the same problems of access to high-quality, timely care are to blame when it comes to fistula treatment. This research demonstrates that women are not able to consistently access high-quality fistula surgeries. They are forced to wait for months or even years for interventions while living away from their husbands, communities, and kin at clinic compounds. When women in this sample did undergo surgeries, the majority did not attain continence.

This study found that women are waiting at clinics for extended periods of time. Women frequently wait on center compounds without any idea of if or when they will be scheduled for surgery. For example, Aïshatou, a twenty-five-year-old Tuareg woman explained, "to me, Niamey was as far away from my home as I could imagine. After Niamey, there was only the great unknown. I cried for three days before leaving my village. But I was assured that here they would fix me. Here I'd regain my life." Unfortunately, Aïshatou had been waiting at Dimol for over a year and still had not even been consulted by a

doctor. She 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." She added, "now, I don't know what I am even waiting for."

While Harouna et al. (2001), Maulet et al (2013), Ndiaye et al (2009), and Meurice et al. (2016) have all remarked upon a similar trend of long wait times in Niger's fistula centers, this research builds upon these findings and suggests that wait times may be substantially longer than previously recorded and more destructive to women's social lives than previously understood.[12-15] In a study at Niamey's National Hospital, Harouna et al. found that 45.5% of women had waited between six months to one year, while 34.5% had waited more than one year.[12] In an 18-month cohort study conducted with women with fistula in Niger and Mali, Maulet et al. found that the median time spent in fistula centers during the study period was seven months.[13] Additionally, it was the women who failed to gain continence who lingered at centers, eight of whom did not leave the center at all during the entirety of the 18-month study.[13] These long absences from home in the search for care compound women's social problems dramatically. The current research found that prolonged absence from home in search of treatment often has detrimental effects on women's social lives, resulting in increased social marginalization and social stigma because of the strain long absences place on women's social ties, which begin to fray and then rupture as women become increasingly peripheral to their community, kin, and romantic partners.[16] The severity of the attenuation of these social fabrics tends to be directly related to the length of time a woman is absent for treatment. These findings have implications for fistula clinic staff, who may work to reduce the amount of time women spend at centers and away from home. Centers might also reconsider or individualize lengthy pre- or post-surgical "reintegration" or "rehabilitation" courses.

While much humanitarian and media messaging proclaims an 85-90% success rate for fistula surgery (see, [17-19]), the 100 women with fistula followed in this study fared much more poorly. Of the 61 women in the sample who underwent fistula surgery, only 36% attained continence during the research period. Outcomes varied slightly by fistula center, ranging between a 31% continence outcome at CNRFO/ Lamordé to 41% at Danja. The 41% continence outcome at Danja can be compared to the center's overall success rate for February 2012 to July 2013 of 49%, reported in an interview by Danja's director.

Women underwent up to 11 previous surgeries, with 33% of women having undergone 4 or more previous total surgeries. Considering that each surgery results in an average stay of nearly six months on the hospital compound, this may translate into years away from home. The confluence of long waits and poor surgical outcomes means that more attention must be focused on how women balance the hope for cure with the risk of social harm, strategically deciding whether or not to abandon or reinitiate their pursuit of surgical cure. Significant research has suggested that fistula is the source of social stigma. However, this research suggests that it may partially be the

lengthy process of seeking treatment in Niger – and not necessarily the condition for which women are being treated – that causes social harm for women back home.

Although all four sites were considered "fistula centers," they were quite distinct, characterized by a varying spectrum of services and opportunities for women. For example, only one of the four sites (Danja) had a fully staffed and functional surgical block, offering women regular surgeries. The vast majority of fistula surgeries available at CNRFO were performed by visiting foreign surgical missions, and thus irregular and subject to long waits. In May 2013, fistula activities at Lamordé were halted. Dimol billed itself as a "waiting and reintegration center," offering women with fistula a place to live, eat, wait, and receive various trainings, but not to receive medical care (although women themselves were unaware of this). Danja offered women activities and various programming; while social programming at Dimol and CNRFO was infrequent, thus offering women little more than a shaded place to spend their days, months, or years waiting. Indeed, the quality and content of "care" in fistula centers across Niger varied remarkably.

The relatively poor surgical outcomes and variability by center highlight the importance of investing resources in fistula repair centers of excellence. Fistula centers should work to radically reduce wait times, improve clinical communication, and increase inter-center collaboration. This study demonstrates the importance of further research on surgical failure, extended wait times, and their social consequences to women.

Funding: *This study was funded by the Wenner-Gren Foundation for Anthropological Research under Grant 8567; the Fulbright Hays under Grant P022A120012-002; the National Science Foundation under Grant 1243775; and the Worldwide Fistula Fund. Thanks to the School for Advanced Research and the Vera Campbell Foundation for an in-residence writing fellowship.*

Conflicts of Interest: *In 2012 the author received a small research grant from the Worldwide Fistula Fund, the 501c3 that runs the Danja Fistula Center.*

References

1. Adler AJ, Ronsmans C, Calvert C, Filippi V. Estimating the prevalence of obstetric fistula: a systematic review and meta-analysis. BMC Pregnancy Childbirth. 2013 Dec 30;13:246. doi: 10.1186/1471-2393-13-246. https://doi.org/10.1186/1471-2393-13-246 PubMed PMID: 24373152; PubMed Central PMCID: PMC3937166.

2. Wall LL. Obstetric vesicovaginal fistula as an international public-health problem. Lancet. 2006 Sep 30;368(9542):1201-9. https://doi.org/10.1016/S0140-6736(06)69476-2 PubMed PMID: 17011947.

3. Institut National de la Statistique (INS) et ICF International, 2013. Enquête Démographique et de Santé et à Indicateurs Multiples du Niger 2012. Calverton, Maryland, USA : INS et ICF International. French https://dhsprogram.com/pubs/pdf/FR277/FR277.pdf

4. United Nations Development Programme, "Human Development Report 2015: Work for Human Development," 2015. [Online]. Available: http://hdr.undp.org/en/2014-report. [Accessed 20 September 2016].

5. The World Bank, "Lifetime risk of maternal death," 2015. [Online]. Available: http://data.worldbank.org/indicator/SH.MMR.RISK. [Accessed 21 September 2016].

6. Prual A, Huguet D, Garbin O, Rabé G. Severe obstetric morbidity of the third trimester, delivery and early puerperium in Niamey (Niger). Afr J Reprod Health. 1998 Apr;2(1):10-9. PubMed PMID: 10214424.

7. IRIN, "Niger: Botched Birth Survivors Battle Fistula," 21 December 2007. [Online]. Available: http://www.irinnews.org/report/75970/niger-botched-birth-survivors-battle-fistula

8. Ahmed S, Genadry R, Défis de la Prévalence de la Fistule Obstétricale au Niger, in UNFPA Atelier de Réflexion Stratégique sur la Fistule Obstétricale au Niger/ UNFPA Conference on a Strategic Reflection on Obstetric Fistula in Niger, Grand Hotel, Niamey, Niger, 8 October, 2013.

9. Holzemer WL, Uys LR, Chirwa ML, Greeff M, Makoae LN, Kohi TW, Dlamini PS, Stewart AL, Mullan J, Phetlhu RD, Wantland D, Durrheim K. Validation of the HIV/AIDS Stigma Instrument - PLWA (HASI-P). AIDS Care. 2007 Sep;19(8):1002-12. https://doi.org/10.1080/09540120701245999 PubMed PMID: 17851997.

10. Kristof N, "The Illiterate Surgeon," The New York Times, pp. Op-Ed, 12 June 2005. http://www.nytimes.com/2005/06/12/opinion/the-illiterate-surgeon.html?_r=0

11. Hamlin C, Little J, The Hospital by the River: A Story of Hope. Oxford: Monarch Books: 2001.

12. Harouna YD, Seidou A, Maikano S, Djabeidou J, Sangare A, Bilane SS et al., La Fistule Vesico-Vaginale de Cause Obstétricale: Enquête auprès de 52 Femmes Admise au Village des Fistules. Sante Tropicale. Médecine d'Afrique Noire. 2001;48(2)55-59.

13. Maulet N, Keita M, Macq J. Medico-social pathways of obstetric fistula patients in Mali and Niger: an 18-month cohort follow-up. Trop Med Int Health. 2013 May;18(5):524-33. https://doi.org/10.1111/tmi.12086 PubMed PMID: 23489380.

14. Ndiaye P, Amoul Kini G, Abdoulaye I, Diagne Camara M, Tal-Día A. Epidemiology of women suffering from obstetric fistula in Niger. Med Trop (Mars). 2009 Feb;69(1):61-5. French. PubMed PMID: 19499737.

15. Meurice ME, Genadry RR, Bradley CS, Majors B, Ganda SO. Identifying barriers to accessing information and treatment for obstetric fistula in Niamey, Niger. Proc Obstet Gynecol. 2016 Aug 18;6(2):Article 1 [13 p.]. Available from: http://ir.uiowa.edu/pog/vol6/iss2/1. Free full text article.

16. Heller A, Hannig A. Unsettling the fistula narrative: cultural pathology, biomedical redemption, and inequities of health access in Niger and Ethiopia. Anthropol Med. 2017 Jan 31:1-15. https://doi.org/10.1080/13648470.2016.1249252 [Epub ahead of print] PubMed PMID: 28140615.

17. Engender Health, "Surgical Repair and Rehabilitation," 2014. [Online]. Available: http://www.fistulacare.org/pages/what-is-fistula/surgical-repair.php. [Accessed 1 February 2015].

18. Clinton Foundation, "Obstetric Fistula in Mali: Women Living with Dignity, Commitment by IntraHealth International, Inc. Clinton Global Initiative," 2014. [Online]. Available: https://www.clintonfoundation.org/clinton-global-initiative/commitments/obstetric-fistula-mali-women-living-dignity [Accessed 1 February 2015].
19. Engender Health, "Surgical Repair and Rehabilitation," 2014. [Online]. Available: http://www.fistulacare.org/pages/what-is-fistula/surgical-repair.php [Accessed 1 February 2015].