ORIGINAL RESEARCH ARTICLE

Obstetric Fistula "Disease" and Ensuing Care: Patients' Views in West-Africa

[1]Nathalie Maulet, [2]Abdramane Berthé, [3]Salamatou Traoré and [1]Jean Macq.*

[1]Institute of Health and Society, Université Catholique de Louvain, Brussels, Belgium; [2]Centre Muraz, Bobo-Dioulasso, Burkina Faso; [3]ONG Dimol, Niamey, Niger

***For Correspondence:** *E-mail: nathalie.maulet@uclouvain.be; Phone: +32 (0)2764 39 36*

Abstract

We explored obstetric fistula patients' real-life experience of care in modern Health System. Our aim was to analyze how these women's views impacted their care uptake and coping. We conducted 67 in-depth interviews with 35 fistula patients or former patients in 5 fistula repair centers within referral hospitals in Mali and Niger. Perceptions of obstetric fistula influenced the care experience and vice versa. Obstetric fistula was viewed as a severe chronic disease due to length of care process, limitation of surgery and persisting physical and moral suffering. We highlight the opportunity to build on patients' views on obstetric fistula trauma and care in order to implement an effective holistic care process. *(Afr J Reprod Health 2015; 19[1]: 112-123).*

Keywords: Vesico-vaginal fistula, long-term care, social perception, chronic disease, qualitative research, West Africa.

Résumé

Nous avons exploré l'expérience de la vie réelle vécue par les patientes de la fistule obstétricale dans le système de santé moderne. Notre objectif était d'analyser la façon dont les points de vue de ces femmes touchées influent sur leur acceptation de soins et comment elle s'y adaptent. Nous avons mené 67 entrevues en profondeur avec 35 patientes de la fistule ou d'anciennes patientes dans les centres de réparation de la fistule dans cinq hôpitaux spécialisés au Mali et au Niger. Les perceptions de la fistule obstétricale ont influencé l'expérience de soins et vice versa. La fistule obstétricale a été perçue comme une maladie chronique grave en raison de la longueur du processus de soins, la limitation de la chirurgie et de la persistance de la souffrance physique et morale. Nous soulignons la possibilité de s'appuyer sur les points de vue des patientes sur la traumatologie et les soins obstétriques fistules afin de mettre en œuvre un processus de prise en charge globale efficace. *(Afr J Reprod Health 2015; 19[1]: 112-123).*

Mots-clés: fistule vésico-vaginale, soins de longue durée, perception sociale, maladies chroniques, recherche qualitative, Afrique de l'Ouest.

Introduction

Obstetric fistula is commonly defined as a vesico- or rectovaginal fistula resulting from prolonged obstructed labour. Lack of access to quality emergency obstetric care (cesarean) is the main underlying cause of fistula continuation in developing countries. This multifaceted birth-injury is coupled with the devastating medico-social consequences of chronic urinary/fecal incontinence[1,2].

A 10-year international campaign to end fistula has increased awareness and boosted implementation of care programs throughout Africa[3]. Likewise, the knowledge base has expanded[4]. Assessment of surgical outcomes, which has been limited to fistula closure for decades, now includes post-surgical residual incontinence[5-8]. The persistence of psycho-social problems despite surgical success has been highlighted in comparative and qualitative studies[9-12]. An increasing interest in the possibilities of pregnancy after fistula surgery has slowly led researchers to investigate reproductive health issues linked to fistulas[13-15].

These new developments have created a change in fistula care perception. Surgery is still paramount but interest in co-morbidities is growing. Nevertheless, most analyses are still based on a before/after repair design[9-12]. Despite scattered data showing that fistula care is expected to include from 1 to several months of stay in a

repair center[16-19], the literature still presents care as a short-term episode. Consequently, care interventions have rarely been studied as such[4]. How care should be provided is mainly addressed through clinical guidance and recommendations[20,21]. Information on care provision is given by western caregivers relating their illuminating experiences in fistula repair centers[22,23]. Interestingly, real-life reports of fistula victims' experiences address difficulties in accessing care and challenges of post-repair reintegration[24-28]. Patients' viewpoints of the care itself are absent from the current fistula literature – or rather are presented similarly in awareness pamphlets and in scientific papers, i.e., a praise for lifesaving surgery[29,30].

This paper explores the real-life experience of obstetric fistula care. We aim to highlight how patients' perceptions impact care uptake and coping. An in-depth understanding of patients' views could open the way to reflect on obstetric fistula care and follow-up.

Methods

Research design

The present qualitative analysis is part of a larger concurrent mixed methods research studying medico-social issues related to obstetric fistula patients in Mali and Niger (2008-2009). In a bottom-up positioning, we considered patients' viewpoints as a pre-requisite for care improvement. Accordingly, we collected descriptive accounts of patients' care process experiences.

Sample

Primary inclusion criteria were age (minimum 16), diagnosis (any type of fistula subsequent to obstructed labor and resulting in chronic urinary/fecal incontinence) and language (Bambara or Fulfulde in Mali and Hausa or Zarma in Niger).

Our sampling procedure was based on spatial and temporal criteria. Spatial triangulation was threefold: (1) country, (2) region, (3) fistula repair center. Patients were recruited in Mali and Niger. Prior to fistula development, participants were living in the regions delimiting our research area (Koulikouro, Segou and Mopti regions in Mali and Tillabery, Dosso, Maradi and West-Zinder regions in Niger). All were or had been admitted to the participating fistula repair center within a general hospital or maternity unit with a permanent in-house local fistula surgeon specialist: in Mali, Teaching Hospital of Point G/Bamako and Regional Hospital of Sominé Dolo/Mopti; in Niger, National Hospital/Niamey, National Hospital of Lamordé/Niamey and Central Maternity Hospital/Zinder.

Time triangulation was twofold: (1) care process and (2) time spent in the fistula repair center. We recruited patients at different stages of their care process so that we would collect a large range of experiences. We also included former patients to collect their retrospective views. The total duration of stay in the repair center was expected to strongly impact on the care experience, but proved impossible to estimate because patients had different mobility patterns[17]. Furthermore, even when using references appropriate to the local culture, participants were often confused about time. We, therefore, used the number of fistula surgeries as a proxy measure of the time spent in the repair center.

Participants (N: 35) were recruited in fistula repair centers (n: 29), through NGOs providing reinsertion support (n: 4) or through the sisterhood method (n: 2). It is to note that 21/29 patients recruited in the fistula repair centers also participated in the quantitative part of our mixed methods research that was explained elsewhere[17]. Their profiles are described separately. In the repair centers, the research was introduced to all patients collectively with the support of care providers and/or social staff. Participants recruited elsewhere were approached on behalf of a trusted person (NGO staff or peer fistula patients).

Fieldwork and data collection

First author conducted all interviews with the help of 1 local female assistant per country. We devoted about 25% of our research time to establishing a rapport and maintaining contact with the participants during 18 months.

Study settings were linked to participants' place of life and sometimes changed during the

course of the research: fistula repair centers or their neighborhoods, towns or remote villages. Intensive presence in a repair center provided us an opportunity to complete our data by direct observations. This was less possible in communities where, for ethical and logistical reasons, we only spent a limited time before and after interviews.

We conducted 67 semi-structured interviews (1 to 7 interviews per patients, mean: 2) Interviews lasted approximately 1 hour, were audio recorded, transcribed and translated into French. Interviews started with an informed consent procedure and were held in a private place.

The research was approved by the University of Bamako's Ethical Committee in Mali and the Ministry of Public Health in Niger; it was subsequently authorized by each surveyed health structure authority.

Analytical framework

A perception is defined as a person/group view based on her/their own system of reference, stemming from interactions and generating meaningful adaptive behaviors[31,32]. Hence, construction of a perception is a dynamic social process.

In order to explore gradual changes in patients' perception of what happened to them; we decided to be coherent with the course of events starting from fistula trauma before moving to care process as such.

Three dimensions influencing perception and potentially impacting care uptake and coping emerged from our data. These 3 interlinked dimensions are our analytical lines: (1) patients' interpretation of obstetric fistula etiology; (2) real-life experience of care; (3) multifaceted suffering.

Findings

Obstetric fistula occurred after the first pregnancy for 19/35 participants. Twenty-four women underwent more than 1 surgical intervention and only 16/35 were continent at the end of our study. Sample profile is summarized in Table 1 and individual characteristics are detailed in Appendix 1.

Table 1: Socio-medical characteristics of women at the end of the study period by type of participation (N: 35)

Characteristics	**Quali only** (P1-P14)	**Quali & quanti** (P15-P35)
Country		
Mali	7	9
Niger	7	12
Age		
Mean (SD)	*29 (8.9)*	*33 (11.1)*
10-19	2	0
20-29	6	9
30-39	5	5
≥40	1	7
Marital status		
Married	7	11
Divorced	6	8
Single	1	0
Widow	0	2
Gravidity		
Mean (SD)	*3.4 (2.2)*	*2.8 (0.8)*
1	4	5
2-4	5	10
≥ 5	5	6
With ≥ 1 child	9	8
Number of surgeries		
Mean (SD)	*1.9 (1.5)*	3.9 (2.6)
0	1	1
1	7	2
2	2	4
3-4	3	8
≥ 5	1	6
Fistula duration [a]		
Mean (SD)	*5.3 (7)*	*11.9 (12*)
0-1	6	1
2-5	4	9
>5	4	11
Incontinence status		
Urinary	3	14
Urinary & fecal	1	1
Continent[a]	10	6

[a] Fistula duration in years

[b]Continence is defined as a closed fistula without any residual or stress incontinence. As per patients' definition: "being dry".

Appendix 1: Participants socio-medical characteristics at the end of the study

Patients ID	Age	Marital status[a]	Gravidity	Gravidity at fistula Occurrence	Number of surgeries	Fistula duration (year)	Years since in center	Incontinence status[b]	With ≥1 living child[c]
P1	27	M	4	4	0[d]	0.5	1	C	1
P2	25	D	1	1	1	4	0	U	0
P3	39	M	6	1	2	16	0	C	0
P4	39	D	1	1	6	10	0	U	0
P5	28	M	5	5	1	1	0	C	1
P6	19	S	1	1	1	0.5	0	C	0
P7	30	M	7	5	2	10	0	U	1
P8	20	D	2	2	4	2	1	C	0
P9	34	D	7	5	1	1	5	C	1
P10	48	D	5	3	1	23	5	U & F	0
P11	20	M	1	1	3	2	4	C	1
P12	18	M	2	1	1	1	3	C	1
P13	35	D	3	1	1	1	2	C	1
P14	25	M	3	1	3	4	4	C	1
P15	40	M	8	7	9	12	0	U	0
P16	50	M	8	1	2	35	1.5	U	1
P17	50	W	8	1	2	30	1.2	U	1
P18	45	M	4	2	4	28	0.6	U	1
P19	60	W	2	1	4	43	0	U & F	1
P20	35	D	4	4	2	4	0	U	0
P21	30	D	1	1	11	17	0	U	1
P22	45	M	2	1	1	4	0	C	1
P23	25	D	1	1	5	8	1.5	C	1
P24	40	D	1	1	7	18	0.2	U	1
P25	32	D	2	1	5	15	0	U	0
P26	26	M	2	1	5	4	0.5	U	1
P27	30	D	10	10	4	1	1	U	0
P28	20	M	3	1	4	5	1.5	U	1
P29	25	M	7	7	0	0.5	1	C	0
P30	25	M	3	1	1	6	1.5	U	1
P31	23	M	1	1	4	5	1	C	1
P32	20	D	1	1	4	2	0	C	1
P33	25	M	4	3	3	6	1.2	C	0
P34	30	D	4	4	3	3	0	U	0
P35	28	M	9	4	2	4	1.5	U	0

[a] Abbreviations: M= married, D= divorced, W= widowed, S = single

[b] Abbreviations: C= continence, U= urinary incontinence, U&F= urinary and fecal incontinence. Continence is defined as a closed fistula without any residual or stress incontinence. As per patients' definition: 'being dry'.

[c] 1= with at least 1 living child, 0= without any living child

[d] Case of spontaneous fistula closure by early insertion of catheter after traumatic childbirth – thus without surgical intervention.

Obstetric fistula occurrence is an extremely traumatic experience. Obstructed labor for a fistula patient generally ends in referral to a health structure providing emergency obstetric care. The cesarean that saved the women's lives – but usually not those of their babies – can generate conflicting feelings towards care providers.

The search for specialized fistula care varies from an immediate patient referral to a long-lasting and difficult quest. Hence, each woman is admitted to a fistula repair center with a set of experiences, feelings and beliefs liable to mark subsequent interactions with modern health care.

Before the care process: the burden of etiology

The *disease of the urine* is the generic term used for obstetric fistula in all 4 languages of our research area (Lexis in Appendix 2). This denomination implies incontinence in Mali and Niger. In Niger, urine disease can also mean urinary infection and, in Mali, can sometimes be

linked with a sexually transmitted infection. The fistula patients disliked this simplistic stigmatizing denomination and were eager to clarify how they got ill.

Appendix 2: Lexicon of local language phrases related to obstetric fistula perceptions

Country /Language	Phrase in local language	Literal translation in English
Niger/Hausa	Ciwon/cutar yoyon/fitsari	Disease/suffering of the flow out of urine
Niger/Zarma	Harmun dooro	Disease of the urine
Mali/Bambara	Sugunè bon bana djiguini kofè	Disease of the urine flowing out after childbirth[a]
Mali/Fulfulde	Niao kebbe so wari e debbo tiagal heptagool	Disease of the urine flowing out without warning in women after childbirth[b]
	Taare so wari	The urine is flowing out[b]
Niger/Hausa	Maara	Low-stomach
	Mafusara	Bladder [c]
Niger/Zarma	Harmun tuwo	Urine cup/pot
Mali/Bambara	Sugunè bara	Urine can
	Sugunè marayoro	Urine bag
Mali/Fulfulde	Sudu tare/kebbe	Urine room

[a]In Mali, when a woman first mentioned she suffers from urine disease, she sometimes added the circumstances under which she got the disease. We hypothesized that it was to avoid stigma; incontinence being sometimes associated with STI.

[b]Note that in Fulfulde, the symptom is sometimes mentioned without even adding the word disease.

[c]In Hausa, women usually said 'the low-stomach' or 'the place where urine is' and used the exact word 'bladder' only when asked to precise 'the exact place where urine is'. In all other languages, the word 'bladder was unknown/unused by our participants.

Our participants highlighted that fistula is a disease given by God; that is they got it by accident and that no one – especially themselves – could be held responsible for it. ''It is God's will'' is a common phrase used as a mechanism of acceptation and/or defense. This first etiological perception is called prosaic as it does not hold any specific symbolic or magico-religious meaning[33]. The prosaic perception emphasizes that causality is considered as plain and natural.

Despite previous statements in the literature[2], fistula was never attributed to a curse during our research. Fistula was linked to a sin of the flesh only in the experience of an unmarried participant who in fact refuted this sentence, appealing to God's will. Although the notion of punishment of deviant behavior cannot be excluded, obstetric fistula is clearly part of "the large category of natural or God's illnesses already identified as common in Islamized West African countries"[34].

It is nobody's fault, I give it to God. […] Hence, nobody can harm me. When my sister-in-law said nasty things to me, I told myself that she was not addressing me but rather God. (P7)

As far as I am concerned, God placed the disease in me. I only know I got it during childbirth. (P28)

A second etiological perception coexisted in fistula patients' minds. We call it a pragmatic perception: women understand that something went wrong during childbirth. Although excessive duration of labor was identified as the major causal factor, it only represented the beginning of women's questioning. Having survived a near-fatal event, our participants all had experienced one or several of the three delays causing maternal mortality (deciding to seek appropriate medical care, reaching an obstetric facility, and actually receiving adequate care)[35]. In the tragic account they gave, they emphasized that these delays were the cause of their urine disease.

The long labor caused this disease. When you are in labor for 2 to 3 days, even if someone brings you to hospital, you might get this disease. (P14)

Someone brought me to a small health center; a student nurse was there. He did not tell us he could not do anything for me. Yet, he did not let me go so that my family-in-law could take me elsewhere. […]When we arrived in [the big] health center, they also threw me into a room without looking at me. I stayed there lying in the delivery room for an hour. I was in great pain. After all this time, they told us they could not do anything and that we should call Y [referral hospital]. Once in Y, I also lay down for a long time with my pain before they came to operate on me. (P4)

Looking further to find a meaning for their fate, participants identified two main causal agents: their unborn child and the care providers. As with labor duration, dystocia was correctly identified as the underlying factor: *baby was stuck and/or tired*. Yet, trauma itself was believed to be due to the unborn baby's hands, feet or hairs injuring the bladder. Another explanation was linked to the women basic understanding of the childbirth process and their own body representation: the baby *took the wrong way, the way of the urine, to come out.*

Prosaic and pragmatic etiological perceptions not only co-exist but have complementary psychological functions. A pragmatic search for a meaning or someone to blame is more or less achieved by the prosaic acceptance process. Our participants paradoxically felt resentful towards care providers who delivered them from dystocia. Some examples of the patients' words reveal the aggression they felt:

It's the long labor; when there is a problem to get the baby out. It's because midwifes are forcefully pulling the baby out. (P26)

When they operated on me [C-section], they cut the urine box. They forgot to stitch it and to put it back in its right place. I lose urine since my surgery. (P5)

I believe that doctors' scissors cut the place where the baby was. This kind of disease doesn't exist back home. People say that it happens when doctors don't know how to operate. (P1)

They [care providers] don't even deserve a look. Aren't they the ones who assassinated my child?! They made a mistake. […] If you go to them, not only do they force you to do the labor but if you don't start, they put iron bars in you [forceps] and they slap you in the face. They even hit me! They are useless. As far as I'm concerned, I don't even want my enemy to be taken to the hospital of X [regional hospital]. (P11)

Despite their dramatic childbirth experience in hospital, and probably because they perceived the disease as resulting from it, women considered modern care as the only way to be cured. Yet, women often wandered between different modern health structures before being directed to an effective fistula repair center. Only a few of our participants initially consulted witchdoctors before turning to modern health care. Women resorted to traditional care for lack of proper referral, because it was close at hand in the community or in an attempt to maintain some social support by complying with local practices and family advice.
The path to care was an integral part of the women's disease experience. Moreover, elapsed time before and throughout care impacted on the women's health and, consequently, their care needs.

During the care process: Domination and limitations of surgery

Once admitted to a fistula repair center, surgery was the main event expected by woman. However, surgery could be delayed if the patient was in a poor physical condition (fistula co-morbidities, malnutrition, malaria, etc.) or because of surgeon workload. Surgery postponement was perceived by the women as poor care organization and potentially jeopardized further treatment. During our fieldwork, we observed reactions going from infinite patience to anger and despair. This delay contributed to perceiving the disease as a long-lasting one.

Three times! My belly was washed up to 3 times [pre-surgery purge]. It was only the fourth time that I was operated on. […] I don't want to go back through all that, because it's exhausting. (P17)

I don't know where they will do the work [surgery]; on the belly or inside [vaginal route]. […] I don't worry about the work itself; I do worry about NOT having the work done. […] Didn't I wait for 3 whole months?! Can someone who waited for 3 months decently go home to come back once again?! (P34)

With the exception of a specific psycho-social care initiative in 1/5 fistula repair centers, individual communication between patients and care providers was scarce. Patients recalled having had a very basic informed consent process. Most

information on disease or treatment was gained from other patients. Expert-patients (incurable or cured women hired to help with daily organization or basic nursing care) were sometimes mentioned as informants. Nurses were seldom mentioned throughout the care process stories.

Table 2: Surgical care as experienced by patients

Informed consent
As God is my witness, they [care providers] told me that they would operate on me and asked what I thought about that? I told them that I came to get my health back, be in good health and be able to be with my friends.[…] *They told me that they would draw the urine tube back to my behind [urinary diversion]. I only told them to do something that would allow me to be cured; that is what I came for. I did not come here to be spoiled; so they should do something good for me. […] If only I had suspected that it might not work, I would never have accepted! (P10)*
Pre-op check up
Once they have listened to your heart and taken your blood pressure, it's done. Only the people who operate on you look down there [gynecological examination]. (P16) *It was medical water. It's like blue but not quite blue [methylene blue]. […] It's to check you properly and find your injury. […] I understood on my own that it's what they do because they do it in twos: one person puts medical water on your genitals, and the other looks inside. He sits and he looks. (P1)*
Operating room
When you arrive, their belongings are everywhere and they [surgeons] start to work. But as soon as they suspect that you are looking, they put a loincloth between you and them. […] *One places a drip. They tell you to sit up and they do an injection into your back. They ask you to lift your feet, so when you cannot, one knows the injection is working. […]* *You see what is happening because you stay awake. Their hands go back and forth. You see iron items passing on your belly. They place irons where they do the surgery. (P3)*
Surgery
They were fixing the urine box. As for the rest, I have no idea at all. […] They stitched it or glued it, I haven't got a clue! (P3) *You see, when you sew a loincloth, you fold it, don't you? Well, that is how they do it. I understood it by myself […]* *No, one sewed on the outside. They stitch inside first and then on the outside. The heat inside your belly will remove the sewing threads. They use little nylon threads. (P6)*
Post-op care
After surgery, you lie down on a bed. You don't feel anything; they give you painkillers. They come to look at you. Yes, they come to see you during the night, in the morning and in the afternoon. They keep coming to check on you at any moment (loitering). (P16)

Women expressed a limited interest in the treatment itself because were eager to be cured. Nonetheless, our participants' care stories show that with the little information grasped, they decoded pre- and post-surgery procedures quite well; surgery itself remaining more obscure. Table 2 relates the main steps of surgical care as understood by patients.

Women logically referred to daily life items to describe their bladder (a pot, a cup, a bag, a can, a room or a place) and what surgeons did to repair it. In their body representation, the bladder appeared as a "container" with the specific function of keeping the urine, like other 'containers' for baby, food or feces. Surgery actually contributed to identify the bladder injury as the biological cause of the disease. It allowed women to locate and picture their injury with the direct consequence of reassuring them on their chances of having another child.

Patients further sharpened their perception through the outcome of their surgery. Here again, a mix of prosaic and pragmatic arguments was used to justify surgical outcome. Women were appealing to *God's will* as a commonplace saying to justify surgery success as well as failure. At the same time, surgery outcomes were pragmatically explained by the existence of several types of urine diseases. The distinction between these types of disease was mainly a function of the perceived etiological agent: obstetric or ''iatrogenic'' fistula.

> *Diseases are not the same. For A, one repairs [holes] one by one. She has little holes. As for me, medical scissors cut the cup of urine and it's a big hole. (P5)*
>
> *For some, the bag of urine moved. Other women have one hole; in that case, it's easier to repair. Others on the contrary have several holes and that's not easy to repair. […] Yes, they stitch the holes. They stitch one hole and leave the others. One can't repair them all together. After 3 months, they'll do another hole. (P4)*

The same ''*one hole at a time*'' perception of surgery was spontaneously expressed in all 5 fistula repair centers: it was said to have been heard from care providers in 1 center and reasoned out by women themselves in the 4 others. While

this perception has the beneficial effect of ease acceptance of surgical outcome, it extends the care process till ''*the very last hole*''. The fact that it postponed the dreaded diagnosis of incurability probably explains the attractiveness of this version for patients as well as for surgeons. Yet, sooner or later, consciously or not, deemed incurable women accepted their fate.

They [care providers] told me that if I come back a third time, it will be over. I was operated on twice but it's not over yet. So, I was supposed to go back a third time. Some women endured 4 surgeries others 5 and yet they're not cured. I don't think its working; their repairs are not working. (P17, decided not to go back for a 3^{d} surgery)

I believe it's not going to work. With each work [surgery] I endure, it gets better but, as soon as one removes the catheter, the urine comes back. God, I am truly in despair. (P4)

Whether experienced or observed, repeated surgery shakes a patients' confidence in treatment. Although absent from fistula trauma etiology, the supernatural element sometimes appeared with repetition of surgical attempts: only a curse could explain repeated failures. One can ask to what extent this justification was linked with the experience of being ostracized by the community. Nevertheless, the woman in question considered any surgeon's effort futile before turning to the intervention of a witchdoctor.

Before, during and after the care process: holistic suffering

Paradoxically, women did not feel the *injury of their urine box*. However, their daily suffering was a core component of their disease experience. Women spontaneously mentioned their physical pain during childbirth and post-surgery stories, but their first statement regarding their fistula was *I do not feel anything in my body*. Fistula co-morbidities then emerged from conversations.

Women first mentioned visible co-morbidities, such as foot drop, that they described as a handicap rather than a source of pain. Invisible co-morbidities followed. Skin excoriation due to constant urine leakage on genitals and thighs appeared to be the main source of chronic pain. Women felt ashamed and wanted to keep it secret from care providers as well as from other patients; a prevailing idea among patients being that chronic excoriations occurred when one was not able *to maintain one's disease*.

Urine flows and causes an open wound on your genitals. […]If you put a loincloth on the wound, it is as if someone was burning you. […] You bear pain alone in your room; you are worried until it goes away. (P2)

All patients agreed that surgery was not a painful procedure. The post-surgery period was experienced as a respite from incontinence but not always from pain. Two main painful after-effects of surgery were the indwelling urinary catheter and scars. Patients' viewpoints differed regarding the permanent catheter placed for 10-14 days post-surgery: some complained of constant pain, others pain only when moving, and others no pain at all. Here again, the prevailing perception was that, as all women were in pain, there was no point in complaining. Community life combined with cohabitation of several ethnic groups influenced the women's propensity to express pain: ethnicity was emphasized to proudly draw attention to ones' stamina. This behavior has already been noted for childbirth[36]. Regarding the fistula, bravery was specifically noted for post-surgery and permanent catheter.

In contrast with the above, women easily complained of numerous "standard" troubles (headaches, constipation, etc.) that they – rightly or not – considered as linked to their fistula condition. All in all, they clearly felt a progressive alteration in their general health status.

Urine disease is disturbing. Since I got ill, I've had no child. I was fat; can't you see how tiny I have become?! […] You're so worried that all you eat turns into water in your stomach. (P17)

When you have this disease, your body gets tired. You always feel miserable. And you can't go near other people. You isolate yourself. You don't want to live anymore. (P2)

Physical troubles were systematically associated with moral torment and interlinked with

social stigma. Impairment of social relationships clearly appeared as a main cause of suffering. Patients acknowledged that moral torment deeply and enduringly affected them. Moreover, lack of social support and stigma were perceived as aggravating factors.

My body is full of hatred. Because of this disease, your husband tells you that he doesn't love you anymore. I keep thinking about that. If nobody assaulted on you because of the disease, you will not feel that way. (P14)

Once I had surgery and it was not successful, I was lost, I even cried.[…] So, I told myself that I was not the only one; that there were some women here who had been operated on 2 or 3 times. But, it's not the same because some people supported them. If nobody helps you, your suffering gets worse. (P7)

Intertwined chronic physical pain and psychological suffering appeared central to the women's experiences. Their perception of obstetric fistula highlighted the main features of a chronic disease: complex causality, prolonged course of illness leading to other illnesses and associated with disabilities. Repeated surgery, cases of residual incontinence and stagnation of deemed incurable' patients in repair centers implies that the urine disease is difficult to cure completely. Unfortunately, provision of psychological support, chronic pain management and tertiary prevention, were the most notable absentees from our participants' care stories.

Discussion

Neglected etiological perceptions

In line with classical anthropological studies of disease representations[37], our research highlighted that several etiological perceptions co-existed and evolved as the urine disease took hold of a woman's body and soul.

Furthermore, fistula perceptions and care experiences influenced one another. In a cultural framework encouraging acceptance of one's fate, an interpretation of fistula etiology as resulting from childbirth medical care (Caesarean) directed women straight to modern health care. Within fistula repair centers, evolution of perceptions of fistulas appeared to be determined by real-life experiences of surgery and social interactions among patients. The duration and course of care also impacted patients' perceptions with a boomerang effect on their suffering and ensuing care behavior.

In the current literature, the etiological perception of obstetrical fistula is limited to a listing of perceived causes. Patients'[38,39], community[40,41] and care providers'[42] listings are usually intended to support prevention initiatives. Sensitization messages are often based on this superficial understanding of local perceptions. Moreover, perceived causes are mostly considered as misconceptions to correct; denying them a role in the coping process.

Our in-depth analysis emphasized that patients' views are rooted in their culture and real-life experiences. As such, they represent a valuable starting point for psycho-social counseling. To our knowledge, only two scientific evaluations of counseling programs have been published to date. An Eritrean intervention confirmed the positive effects of individualized and culturally adapted counseling on patients' ability to cope[43]. In Benin, a case-control study demonstrated the significant impact of a combined education and physiotherapy program on continence outcomes[44].

Our patients' confidence in modern health care - as opposed to traditional care - is coherent with a study of surgery outcome perception in Malawi[45]. However, another study in North Nigeria attributed delay of care to patients antipathy towards modern care[46].

Our longitudinal approach qualified these findings: confidence depended on a complex set of factors and varied during the care process. More research is needed to explore other coping factors from admission to final discharge.

The contribution of our study lies in its longitudinal approach over the period of care, but it also has some limitations. Our work concerned fistula patients who had been influenced by their contacts and stay(s) within the Health System. As such, their perceptions might not be representative of all obstetric fistula victims. Because our participants' profiles and real-life experiences are quite diversified and their perceptions juxtaposing,

it was not possible to compare the women's views based on their health or social characteristics.

Our sample only included women treated in fistula repair centers within a referral hospital. The same analysis in a stand-alone repair center may have given noticeably different results. Nevertheless, our analysis should not be considered as an evaluation of a certain type of repair center.

We tried to achieve a good compromise between anthropological depth and the practicality of our public health objective. Therefore, we did not go in-depth into women's anatomic body representation. Patient suffering unsurprisingly highlighted conflicting social interactions and stigma. These aspects were deliberately overlooked as they were beyond the scope of this paper. Finally, due to lack of back translation, we cannot exclude translation bias.

Neglected care process

Patients' care stories reflected the predominance of surgical repair on co-morbidity management. Consequently, patients tended to consider themselves as not entitled to care apart from surgery. The free or nearly free fistula care also curbed any "extra" care requests. In addition to the fistula repair centers' organization and patients' community practices within it, duration of stay appeared as a strong determinant of patients' attitudes towards their care.

When women benefited from some kind of psychological support, they attributed it to NGO staff and, failing that, to their co-patients. Our observations over 18 months and our conversations with patients led us to believe that psychosocial sequela and pain management were disregarded during care – except for the surgical episode.

Overall, women felt that they were "on hold" during their care process. Waiting times before and after surgery along with repeated surgery reinforced perception of fistula as a chronic disease.

Conclusion

World Health Organization guidance recommends a multidisciplinary and holistic approach to fistula care[21]. The holistic approach is also a standard recommendation of most scientific papers on the subject. Yet, this approach is neither implemented in a structured manner in West Africa nor has it been researched in-depth. We believe this lapse is the result of three factors.

Firstly, in the "prevention-treatment-reintegration" triad recommended for fistula programs, prevention and reintegration are usually considered as complex processes whereas treatment is viewed either as a medical procedure or as a benchmark; hence, the lack of feedback on care experience, organizational and non-surgical components.

Secondly, patients' perceptions of fistula as a chronic disease stressed the need of long-term care and tertiary prevention measures. This necessitates an effective understanding of patients' global suffering, but the lack of valid data on the burden and social implications of fistula have already been underlined in the literature[4,47].

Thirdly, implementation of holistic care is a challenge for any Health System; a fortiori those in low resource countries. Some stand-alone fistula hospitals and international NGOs may venture into this realm[48,49]. The task may be less easy for fistula repair centers integrated within referral hospitals, as they are more inclined to biomedical care and overwhelmed by emergencies[21].

Our research calls for the integration of the "burden of care" within the scope of fistula research. Patients' information and psychosocial counseling throughout the care process should be considered as an essential component of obstetric fistula management.

The holistic approach represents the real challenge for obstetric fistula care and research.

Contribution of authors

Nathalie Maulet conceived, designed and conducted the study; analyzed data and wrote the initial draft of the manuscript. Abdramane Berthé, Salamatou Traoré and Jean Macq revised subsequent drafts of the manuscripts. All authors read and approved final manuscript.

Acknowledgements

Sincere thanks to all fistula patients participating

in this study and to our tireless local assistants: A Thiam/Mali and RH Bako/Niger. Acknowledgements to staff of fistula repair centres: Niamey National Hospital, Lamordé National Hospital, Zinder Central Maternity, Bamako' Point G University Hospital and Mopti Sominé Dolo Regional Hospital as well as Fistula Network Eradication/Ministry of Public Health, NGO Dimol and LASDEL in Niger, and NGO Delta Survie, Iamaneh and Médecins du Monde in Mali.

UNFPA/Mali, UNFPA/Niger and WHO/Niger partially funded logistics of first year of data collection; they were not involved otherwise. We further declare no conflict of interest.

References

1. Arrowsmith S, Hamlin EC, Wall LL. Obstructed labor injury complex: obstetric fistula formation and the multifaceted morbidity of maternal birth trauma in the developing world. *Obstet Gynecol Surv* 1996; 51(9):568-574.
2. Wall L.L., Arrowsmith S.D., Briggs N.D., Browning A., Lassey A. The obstetric vesicovaginal fistula in the developing world. *Obstet Gynecol Surv* 2005; 60(7 S1):S3-S51.
3. Velez A, Ramsey K, Tell K. The Campaign to End Fistula: What have we learned? Findings of facility and community needs assessments. *International Journal of Gynecology & Obstetrics* 2007; 99(Supplement 1):S143-S150.
4. Zheng AX, Anderson FW. Obstetric fistula in low-income countries. *Int J Gynaecol Obstet* 2009; 104(2):85-89.
5. Goh JT, Browning A, Berhan B, Chang A. Predicting the risk of failure of closure of obstetric fistula and residual urinary incontinence using a classification system. *Int Urogynecol J Pelvic Floor Dysfunct* 2008; 19(12):1659-1662.
6. Browning A. Risk factors for developing residual urinary incontinence after obstetric fistula repair. *BJOG* 2006; 113(4):482-485.
7. Nielsen HS, Lindberg L, Nygaard U, Aytenfisu H, Johnston OL, Sorensen B et al. A community-based long-term follow up of women undergoing obstetric fistula repair in rural Ethiopia. *BJOG* 2009; 116(9):1258-1264.
8. Browning A, Menber B. Women with obstetric fistula in Ethiopia: a 6-month follow up after surgical treatment. *BJOG* 2008; 115(12):1564-1569.
9. Alio AP, Merrell L, Roxburgh K, Clayton HB, Marty PJ, Bomboka L et al. The psychosocial impact of vesico-vaginal fistula in Niger. *Arch Gynecol Obstet* 2011; 284(2):371-378.
10. Umoiyoho AJ, Inyang-Etoh EC, Abah GM, Abasiattai AM, Akaiso OE. Quality of life following successful repair of vesicovaginal fistula in Nigeria. *Rural Remote Health* 2011; 11(3):1734.
11. Browning A, Fentahun W, Goh JTW. The impact of surgical treatment on the mental health of women with obstetric fistula. *BJOG* 2007; 114(11):1439-1441.
12. Goh JT, Sloane KM, Krause HG, Browning A, Akhter S. Mental health screening in women with genital tract fistulae. *BJOG* 2005; 112(9):1328-1330.
13. Aimakhu VE. Reproductive functions after the repair of obstetric vesicovaginal fistulae. *Fertil Steril* 1974; 25(7):586-591.
14. Bangser M, Mehta M, Singer J, Daly C, Kamugumya C, Mwangomale A. Childbirth experiences of women with obstetric fistula in Tanzania and Uganda and their implications for fistula program development. *Int Urogynecol J* 2011; 22(1):91-98.
15. Wilson AL, Chipeta E, Kalilani-Phiri L, Taulo F, Tsui AO. Fertility and pregnancy outcomes among women with obstetric fistula in rural Malawi. *Int J Gynaecol Obstet* 2011; 113(3):196-198.
16. Coombes R. Supporting surgery for obstetric fistula. *BMJ* 2004; 329(7475):1125.
17. 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; 18(5):524-533.
18. Nafiou I, Idrissa A, Ghaichatou AK, Roenneburg ML, Wheeless CR, Genadry RR. Obstetric vesico-vaginal fistulas at the National Hospital of Niamey, Niger. *International Journal of Gynecology & Obstetrics* 2007; 99(Supplement 1):S71-S74.
19. Ndiaye P, Amoul KG, Abdoulaye I, Diagne CM, Tal-Dia A. [Itinerary of women suffering from obstetric fistula in Niger]. *Med Trop (Mars)* 2009; 69(1):61-65.
20. Constantine G. Practical obstetric fistula surgery. *The Obstetrician & Gynaecologist* 2013; 12 (1)(66).
21. World Health Organization. Obstetric Fistula: Guiding principles for clinical management and programme development. Geneva: WHO; 2006.
22. Ng'ang'a N. Women of the courtyard. A nurse's journey to treat obstetric fistulae in Niger. *AWHONN Lifelines* 2006; 10(5):410-417.
23. Kent A. Working in a fistula hospital. *Practising Midwife* 2010; 13(4):15-16.
24. Khisa AM, Nyamongo IK. Still living with fistula: an exploratory study of the experience of women with obstetric fistula following corrective surgery in West Pokot, Kenya. *Reprod Health Matters* 2012; 20(40):59-66.
25. Mselle LT, Moland KM, Evjen-Olsen B, Mvungi A, Kohi TW. "I am nothing": experiences of loss among women suffering from severe birth injuries in Tanzania. *BMC Womens Health* 2011; 11:49.
26. Mselle LT, Evjen-Olsen B, Moland KM, Mvungi A, Kohi TW. "Hoping for a normal life again": reintegration after fistula repair in rural Tanzania. *J Obstet Gynaecol Can* 2012; 34(10):927-938.
27. Mwini-Nyaledzigbor PP, Agana AA, Pilkington FB.

Lived experiences of ghanaian women with obstetric fistula. *Health Care Women Int* 2013; 34(6):440-460.
28. Yeakey MP, Chipeta E, Taulo F, Tsui AO. The lived experience of Malawian women with obstetric fistula. *Cult Health Sex* 2009; 11(5):499-513.
29. Aliyu F, Esegbona G. Living with obstetric fistula. *BMJ* 2011; 342:d2881.
30. Wall LL. Fitsari 'dan Duniya. An African (Hausa) praise song about vesicovaginal fistulas. *Obstet Gynecol* 2002; 100(6):1328-1332.
31. Jodelet D. Les représentations sociales. Paris: PUF; 1991.
32. Flament C. Structures, dynamiques et transformations des représentations sociales. In: Abric J-C, editor. Pratiques sociales et représentations. Paris: PUF; 2003. 12-37.
33. Olivier de Sardan J-P. La logique de la nomination. Représentations fluides et prosaiques de deux maladies au Niger. Sciences sociales et santé 12[3], 15-45. 1994. Anthropologie de la maladie: nouveaux lieux, nouvelles approches.
34. Olivier de Sardan J-P. La représentation sociale des maladies: des modules? In: Jaffré Y & Olivier de Sarda, editor. La construction sociales des maladies: les entités nosologiques populaires en Afrique de l'Ouest. Paris: PUF; 1999. 15-40.
35. Thaddeus S, Maine D. Too far to walk: maternal mortality in context. *Soc Sci Med* 1994; 38(8):1091-1110.
36. Olivier de Sardan J-P, Moumouni A, Souley A. L'accouchement c'est la guerre. Grossesse et accouchement en milieu rural nigérien. [1]. 2001. Niamey, LASDEL. Etudes et Travaux.
37. Herzlich C. Health and illness: a social-psychological analysis. 3d ed. London: Academic Press; 1992.
38. Nathan LM, Rochat CH, Grigorescu B, Banks E. Obstetric fistulae in West Africa: patient perspectives. *Am J Obstet Gynecol* 2009; 200(5):40-42.
39. Hassan MA, Ekele BA. Vesicovaginal fistula: do the patients know the cause? *Ann Afr Med* 2009; 8(2):122-126.
40. Tebeu PM, de Bernis L., Boisrond L, Le Duc A., Mbassi AA, Rochat CH. [Knowledge, attitude and perception about obstetric fistula by Cameroonian women]. *Prog Urol* 2008; 18(6):379-389.
41. Zheng AX, Harrington AH, Love SA, Thelemaque LD, Anderson FW. Fistula awareness among sisters of women with fistula. *Int J Gynaecol Obstet* 2013; 120(3):232-235.
42. Kazaura MR, Kamazima RS, Mangi EJ. Perceived causes of obstetric fistulae from rural southern Tanzania. *African Health Sciences* 2011; 11(3):377-382.
43. Johnson KA, Turan JM, Hailemariam L, Mengsteab E, Jena D, Polan ML. The role of counseling for obstetric fistula patients: Lessons learned from Eritrea. *Patient Educ Couns* 2009.
44. Castille YJ, Avocetien C, Zaongo D, Colas JM, Peabody JO, Rochat CH. Impact of a program of physiotherapy and health education on the outcome of obstetric fistula surgery. *Int J Gynaecol Obstet* 2013.
45. Yeakey MP, Chipeta E, Rijken Y, Taulo F, Tsui AO. Experiences with fistula repair surgery among women and families in Malawi. *Glob Public Health* 2011; 6(2):153-167.
46. Onolemhemhen DO. Combating Vesico Vaginal Fistula in Northern Nigeria: The Transformation of Women's Health in Africa. *Social Development Issues* 2000; 22(2-3):32-38.
47. Roush KM. Social implications of obstetric fistula: an integrative review. *J Midwifery Womens Health* 2009; 54(2):21-33.
48. Tayler-Smith K, Zachariah R, Manzi M, van den Boogaard W, Vandeborne A, Bishinga A et al. Obstetric Fistula in Burundi: a comprehensive approach to managing women with this neglected disease. *BMC Pregnancy Childbirth* 2013; 13(1):164.
49. Williams G. The Addis Ababa fistula hospital: an holistic approach to the management of patients with vesicovaginal fistulae. *Surgeon* 2007; 5(1):54-57.