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**Reflections on Identity: Narratives of Obstetric Fistula Survivors in North  
Central Nigeria.**

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**Abstract**

Obstetric fistula is a condition that affects women and can lead to identity changes because of uncontrolled urinary and/or fecal incontinence symptom experiences. These symptoms along with different emerging identities lead to family and community displacement. Using narrative inquiry methodology that concentrates on the stories individuals tell about themselves; interviews were conducted for 15 fistula survivors to explore their perception of identities of living with obstetric fistula. Within a sociocultural context these identities consist of the ‘Leaking’ identity, ‘Masu yoyon fitsari’ (leakers of urine) identity, and the ‘Spoiled’ identity, cause stigmatization and psychological trauma. The ‘Masu yoyon fitsari’ identity however built hope and resilience for a sustained search for a cure. Identity is a socially constructed phenomenon and the findings reveal positive community involvement which reduces obstetric fistula stigmatization and improves women’s identity. Sexual and reproductive health issues remain of grave concern within a contextualized societal identity of women’s role.

**Keywords:** obstetric fistula, Nigeria, social identity, stigmatization, psychological trauma, resilience, narrative method

## **Introduction**

Obstetric fistula is an injury sustained by women through an obstructed labor during childbirth. The injury causes an abnormal opening between the bladder and vagina and/or the rectum leading to urinary and/or fecal incontinence (Bangser, 2006; Hardee, 2012; Lewis Wall, 2006). In developed countries, advances in obstetric care have eradicated the condition, however, in developing countries it remains a neglected chronic condition (Cook, Dickens, & Syed, 2004; Hardee, 2012; Wall, 2009; Lewis Wall, 2012).

Women suffering from this condition see their lives revolve around coping strategies to avoid leakage and reduce odor in order to reduce social stigma and to maintain family and community relationships (Barageine et al., 2015). Obstetric fistula affects three overlapping dimensions of women's lives: firstly, it disrupts bodily integrity through impairment, continuing ill health and reduced strength and vigor. Secondly, it disrupts the household economy, causing loss of productivity and debt. Thirdly, it disrupts women's social identity and stability, causing loss of social status in the household, and community (Cook, 2004; Wall, 2006; Filippi et al, 2007; Storeng, 2010).

The body is the object through which the consciousness acts out and connects to its world, hence the chronic illness experiences of living with fistula can cause a rupture between this relationship (Williams, 1984). Identity is socially constructed according to the prevailing system of signs, values and principles and it affects an individual's behavior and cognitive processes (Giddens, 1991; Karnilowicz, 2011). According to the 'identity and social identity theory', the self in a reflexive way can assume itself to be an object, it then labels itself in certain ways in relation to other social categories (Stets & Burke, 2000). Additionally, illness or the risk of illness involves the self-experiencing the illness examining selves and identities within the lens of the prevailing sociocultural environment (Ouellette, 1999). The redefinition of self and identity is a process where coping mechanisms are crucial in adapting

to the ill physical self (Leventhal, Idler, & Leventhal, 1999). Lively and Smith (2011), highlight increasing sociological interest in the relationship between illness and identity, especially in public and private self-perception of identities and their interdependence. The study seeks to understand the identities fistula survivors ascribe to themselves and explores the impact of these identities through the process of their illness experiences. In doing this, we drew on the identity and social identity theory to explore the process of identification as it relates to women's illness experiences.

### **Method**

The study design used narrative inquiry. Narrative inquiry concentrates on the stories individuals tell about themselves (Creswell, 2007). The data collection process involved in-depth interviews to “gather, analyses and interpret stories people tell about their lives” (Marshall, 2011, p.151).

### **Study Setting**

Nigeria is in the western region of Sub-Saharan Africa. In Nigeria, obstetric fistula is a major public health problem with an incidence of 12,000 cases annually, and an estimated 150,000 prevalent cases, and contributes 15% to the global burden of the disease (Federal Ministry of Health (FMOH), 2013). Maheu-Giroux et al. (2015) estimate, Nigeria had 46,800 women living with fistula, making it the fourth highest globally.

The northern region of Nigeria has the highest prevalence of obstetric fistula (0.5% as against 0.3% of the Southern region (NPC & ICF, 2009)). The Northern region has been reported to have lower utilization of maternal health services than the South (Galadanci, et al. 2007; Mallick, Dahiru, & MacQuarrie, 2016; NPC & ICF, 2009, 2014).

### **Sampling and Recruitment**

A purposive method of sampling was used, to identify women that fitted the inclusion criteria and thus able to answer the research question at Evangel Vesico vaginal Fistula Centre

(EVVF), Bingham University Teaching Hospital, Jos, Northern central Nigeria. In qualitative research, purposive sampling is used to identify and select information related to the phenomenon of interest (Creswell, 2007; Palinkas et al., 2015). Hence, women who had been diagnosed with obstetric fistula, had undergone fistula repair, had participated in the rehabilitation program and had returned to live in the community for minimum of 1 year were included.

### **Participants**

The names of 20 women that met the inclusion criteria, and had phone contact numbers were first identified through hospital records with the rehabilitation program coordinator (dating from 2002 when rehabilitation services commenced to 2016, the study year). The initial contacts via phone yielded only six women. Additionally, through physical contacts during the [Blinded organization] reunion program, which coincided with the study period, the research team contacted five women. Nine additional women were recruited through snowballing from the first contacts, making a final total of the 20 initial participants. Five women were excluded, (two were non-obstetric fistula (congenital) and three were still living in the rehab village).

The 15 women that met the inclusion criteria were aged 14 - 42 years at the time of fistula development. Six women had completed primary education, four had secondary education; one had koranic education; while three had no form of education. At the time of fistula development, seven women were subsistence farmers; seven had no form of occupation, while one was a student in secondary school. For nine of the women, fistula occurred at the first delivery, while for the remaining six, it occurred between the second and fifth deliveries. While living with fistula, five remained married, and four were divorced, three separated, two were single and one was widowed. Further demographic characteristics of Post Fistula treatment is provided in Table 1 (INSERT TABLE 1 HERE).

## **Data Collection**

The data collection process was facilitated by Hannah Degge; she was introduced to participants at study site. Interviews took place over a two-month period, but trust and relationship were concretized during the last two weeks after joint participation in the study site's fistula survivors' reunion program. Participants had between 2- 4 interviews each, with a mean length of interviews of 114 minutes. An episodic narrative interviewing method generated data. It involves interviewing participants on situations relevant to the research question in which they have had an experience (Nettleton, 1995). The interviewer asked participants to tell their story regarding their experience of living with fistula. An interview guide provided prompts to explore specific episodes relating to the research objectives that participants might not have mentioned. Interviews were conducted in the local Hausa language by first author assisted by a research assistant. Audio recordings were undertaken, transcribed, and translated by a native speaker. Comparisons were made between the transcriptions and the researchers' raw data field notes. Translated transcripts were reviewed by listening repeatedly to the recordings by the researcher with another native speaker carrying out a back translation of a sample of transcripts. ~~The back translation was done by translating the sample transcripts into the native language to compare with the original transcripts.~~

## **Data Analysis**

Data were analyzed using narrative analysis following Emden's (1997) 2-path procedure of core story creation, and emplotment. The emplotment process identified subplots within core stories resulting in the recognition of three main sets of events that were common to all stories. The construction of three plots that recognized the importance and the function of the

‘individual events’, and a joining together [of these] as a single story (Emden, 1998). The ‘events’ are the elements of the stories that signified the participants’ lives as related by them, in the form of ‘people, places, happenings, thoughts, and feelings’- the ‘grasping together’ is the sense making of the whole events as one story by the narrative researcher (Emden, 1998, p. 37). The plot focused on in this article is the ‘fistula ordeal’ plot, specifically the events that focused on ‘living with fistula’ and ‘coping with fistula’ were those used. The text analysis was carried out by comparing and contrasting the individual textual locations within the narrative constructions (Flick, 2014). The multiple interpretations were grouped as typologies in describing the subjective interpretation of the bodily awareness of living with incontinence.

### **Ethics**

Ethical approval was obtained from the Faculty of Health Sciences, University of Hull, United Kingdom (REF206) and Bingham University Teaching Hospital, Jos, Nigeria (NHREC/21/05/2008/00208). Participants received information (in their native Hausa language) about the study’s purpose and their right to participate or withdraw and signed/thumbed printed a consent form. No woman withdrew from the study.

### **Results**

The commencement of incontinence triggered a series of interlinked chain reactions. The perception of self-changed with bodily awareness stimulated and generated varying issues. The results are presented as, ‘identity changes of fistula survivors’; and ‘consequences of identity changes’.

### **Identity Changes of Fistula Survivors**

The three identities were 1) 'leaking identity', 2) 'group identity/Masu yoyon fitsari' (leakers of urine), and 3) 'spoiled identity'.

### *Leaking Identity*

The name 'mai yoyon fitsari' (leaker of urine) sometimes shortened to 'mai yoyo' (the leaking one) is a local Hausa name given to incontinent woman. The urine conferred on women the feeling of an identity defined by the leakage, causing shame and discomfort. Women viewed this new self as a person that had lost value in by this sign of recognition linked with the leakage. There was also recognition of the new self as very different from whom they really were. Women, irrespective of their ages or marital status, narrated how the changes influenced their self-worth and dignity as women, triggering psychological trauma:

I knew I smelt because of the urine leaking so I did not want to go into the midst of people (20 yrs, VVF, single)

If people come and sit down, I will be ashamed to stand up among them, so I will sit and wait for them to leave before I get up even if I have food on the fire, I will sit there even if the food is burning (42 yrs, RVF and VVF, separated)

I used to see myself as someone whose value has reduced... My value as a woman has reduced...my life has been cut short... (25yrs,VVF, married)

For most women, the incontinence flow limited socializing and restricted movements because of personal hygiene concerns; this invariably resulted in isolation and feeling of self-consciousness. The untoward consequence of this was its effect upon social and economic livelihood. Women without immediate family support became destitute without means of daily sustenance:

I was unable to do anything... (long pause) I had no food... I will send my daughter to my parents who will help me. At a point they were saying if I cannot cope, I should return home (42yrs, RVF and VVF, separated)

Family income became accessible, mostly from the natal family, as members sold property or livestock to meet costs of seeking a cure.

### *Masu Yoyon Fitsari*

The name 'masu yoyon fitsari' is a known Hausa name for incontinent women. The 'Masu yoyon fitsari'- meaning the 'leakers of urine' identity was a 'positive' identity. This positivity is however linked to the benefits of 'joining the group'. This identity became known to women on relating with other fistula survivors who disseminated the information about repair centers as mentioned in the women's narratives. This encounter highlights the temporality feature of the identities, a shift from 'mai yoyo' (leaker of urine) to 'masu yoyon fitsari' (leakers of urine), the realization that there was someone or others in a similar condition. This realization facilitated a shift from the negative thoughts of hopelessness and despair to positive thoughts of hope of recovery. In some cases, survivors served as escorts to the repair center:

I was there with the urine for three years... Later we heard about blinded town through a woman that had been treated here...the woman heard about me and came to look for me...so I told my elder brother that there is news, this time it is about blinded town and I cannot keep sitting down with this sickness (problem) (20 yrs, RVF and VVF, divorced)

Joining the 'Masu yoyon fitsari' (leakers of urine) was the beginning of a hope for cure, as finding women with similar conditions quelled their fear and feelings of shame if soiling happened in public. The development of strong kinship and the psychological healing effect evidenced further the positivity in the identity, which was demonstrated by the friendships formed through realization of shared common symptoms, and their ability to live in an environment without being stigmatized. Hence, women experienced a psychological healing effect through interaction at the repair center as feelings of shame and apprehension were



replaced with acceptance and hope of recovery. Thus, a number of interviewees noted that this was the commencement of their journey to recovery. For example:

...When I got here I was relieved when I saw other women in the same condition, my real fears came down. I stopped being ashamed, even if I was wet, I started feeling at peace with myself, I stopped thinking like I used to in the pasts, on seeing all the women like me. My fears all left, I felt relieved...(32 yrs, VVF, Married)

... (26 yrs, VVF, married)

Fistula survivors provided care when family members were unsupportive. Women often stepped into the care-giving role naturally by providing support, with the group identity playing a prominent role:

That woman started nursing me... I never knew the woman before, but we spent two days with that woman helping to care for me before my aunt from blinded town came (20 yrs, VVF, widow)

For women with persisting incontinence issues after repair, this meant prolonged hospital stay, and it enabled kinship and long-term friendship. The friendship links formed through the group identity eased rejection, particularly for women stigmatized by family due to persisting incontinence despite treatment. Hence, their preference for an elongated continued stay at the repair center and a reluctance to return home after treatment:

Honestly, I am no longer friends with friends that are healthy, honestly, I will not hide it from you...my friends...all my friends are those with leaking urine... people with my sickness. Why, because when I go among them I am not comfortable... I am so sad when I have to go home...happy when I am returning here each time (7 repairs, severe incontinence 22 years)

Our going back home... 'Kai'... was because they drove us away from here... not because we wanted to go back, really, we did not want to leave this place. You needed to have been here to see how we were... (4 repairs, mild incontinence 15 years)

Together, these accounts have shown the ways in which the interviewees perceived their new identity in positive lights, especially as they began to associate with other women who had a similar health condition. This association not only affected their identity positively, but also provided a glimpse of hope of finding cure for their health condition.

### ***Spoiled Identity***

Another consequence of fistula was its negative impact upon sexual and reproductive activity. The sexual and reproductive health issues triggered off the spoiled identity. This identity was viewed mainly from the perspective of the 'damage' on womanhood. This identity occurred parallel to the other two identities. In the narratives, sexual difficulties were more prominent among the married. However, single and divorced/separated women also report the loss of sexual desires and cessation of sexual activity since developing fistula. They attributed this to experiences of psychological trauma, ill-treatment and fear of fistula recurrence if they became pregnant. Conversely, for the still married, the cessation of sexual activity was due to hygiene issues, penetration difficulties, and leakage during intercourse. For some women, especially those without living children, sexual activities ceased abruptly after the commencement of the leakage. Cessation of sexual activity was a consequence of their partner's change of attitude towards them sexually and by sleeping arrangement changes. The women interpreted their spouses' loss of sexual desire as a rejection because their body was considered offensive:

He does not come close to me let alone talk about sex... There was a new room that was built, he just moved in there, so we were in different rooms. I have become

offensive to him now that to even greet me was a problem talk less of sex... (23 yrs, VVF, divorced)

Conversely as earlier stated, for three participants who all had living children, their partners were undisturbed by the leakage, hence felt differently. One of the women tried to use sex to negotiate assistance from her spouse to seek treatment:

I got this problem during my first delivery but despite the urine leakage, we have had two more children with him (40 years, mild leak, 3 children).

When the girl that I gave birth to started walking, he began to come close, but I told him that I cannot because of the problem I have. I asked him to help me check for another hospital, but he said he will rather go and look for another wife that he will not continue to suffer because of me (52 years, dry, 5 children).

For women with the spoiled identity, this caused strain on family relationships and worsened the physical, psychological, social and economic effects, and for some, led to divorce and/or separation. However, in some cases women remained in their matrimonial homes, but their husbands married a second wife (see Table 1). Polygyny is an acceptable practice in some of the cultures; hence, the development of fistula provided the impetus for men to seek another wife. Women expressed feelings of frustration over the addition of another wife and the deterioration in their own marital relations. This was more prominent for women who experienced stillbirth for the index pregnancy and infertility issues because of fistula despite repair.

The difficulties married women experienced in sexual relation and reproductive health, following fistula development were not all alleviated by repair. Some women still observed leakages and penetration difficulties during sexual intercourse, hindering sexual relations. Additionally, some women observed changes to their menstrual flow. Furthermore,

childlessness post repair contributed to continuing family tension. Additionally, within the community, labelling (black listing) was involved:

I am not getting the blessing of wedlock...the fruit of the womb... I am being mocked every day to the extent that my husband has now taken a second wife because I have not given birth again. Sometimes he will say that he is not going to waste his time because even if he sleeps with me, I will not give him a baby, sometimes he will say he doesn't feel good entering me since I have had that problem, he feels disgusted...with me (32 yrs, VVF, dry, married)

~~VVF has affected me...as a woman... since I got this problem, I have never conceived again... I stayed with my (second) husband for one year and did not conceive... when I was planning to remarry, people in the neighborhood started asking why I should marry knowing that I have a problem. Now that I am no longer with him, they were saying that at that time they had asked me why I wanted to marry knowing I have a leaking problem, saying my being sent out was the result of what I have done.....(20yrs, RVF and VVF, mild leak, separated 2x)~~

Interestingly, two women (aged 24 and 42 respectively at time of index pregnancy) with children prior to development of fistula, despite ill feelings about their partners' attitude, wanted to return to their matrimonial homes. However, against their wishes, **despite the spouses remarrying**, these women were forced to live elsewhere, as their spouses were unwilling to accept them despite their dry status:

I was not happy because I wanted to go back to his house but instead I had to go back to my parents' house. I was not happy (4 children, incontinence status, mild leak) I built a small structure that my children and I are living in, not that I have rejected him, not that I have married again...I am there living for him...waiting (5 children, incontinence status- dry)

## **Consequences of Identity Change**

### *Psychological Trauma*

Hygiene issues were challenging because urine and/or feces incontinence affected women's social life and psychological wellbeing. Women described feelings of loss of self-worth, anxiety, despair accompanying identity change, and some described deep persisting sense of hopelessness leading to suicidal inclinations:

I preferred death to living this life. I thought so much.... that I hated myself. It was not a small problem for me. For no one in our village had that kind of a sickness I actually was saying it could have been better if I were dead. At that time, it was a big challenge...You have to deal with people, deal with your smell... I said to myself death is better than that kind of life... I smelled so much... (15 yrs, RVF and VVF, incontinent for 22 years, 7 repairs)

... There was a day I tried to kill myself by drinking cement mixture.... I did this because of the way I felt about my sickness...I was caught before I could drink it... How my life has changed from how it used to be... How I can no longer stay in the company of people. How my life will end up since I did not know what this sickness was and if I would ever get well again (20 yrs, RVF and VVF, incontinent for 2 yrs, 5 repairs, dry status)

Our analysis also shows some of the ways in which the interviewees' experienced psychological trauma, as this resulted in the loss of appetite and weight, because of excessive thinking due to their condition.

### *Identity and Stigmatization*

One of the most striking consequences of fistula was stigmatization in the form of self-stigmatization and stigmatization by others. Self-stigmatization referred to body awareness and fear of people's negative attitudes, or fear of embarrassment because of the leakage:

No, I wasn't going out, I was just sitting at home. I was even afraid of going to church, the fear of my rag dropping in the midst of people and the fear of standing up to find myself all wet in public (32 yrs, VVF, incontinent 3 yrs, 3 repairs, dry)

If you have VVF it confines you, I couldn't go to the places I used to go to as I was used to doing... I used to see myself as someone whose value has dropped; my life has been cut short. Nobody has told me that I am incomplete; it is only me thinking that way (25 yrs, VVF, incontinent 15 yrs, 4 repairs, severe leak)

Interestingly however, no woman experienced stigmatization from the family and from community members at the same time. Where family members such as spouse rejected the woman, the natal family or community took over support:

My parents and my relations said they are tired and left me; I have seen hatred, at that time, all I had to do was just to cry... Whatever I put out for sale, people come, and they buy. If they have not patronized me, I would not have been able to come for treatment (20yrs, incontinent 15 yrs, 2 repairs, mild leak)

He was not doing anything for me, my body is sick, and he will leave (because it was farming season) home without giving me anything to eat. I will be very hungry.

When I saw that the suffering was too much, I left his house back to my parent's house... (23yrs, incontinent 4yrs, 4 repairs, dry)

Acts of stigmatization included separation in living arrangements, (asked to sleep on the floors to prevent mattress spoiling, pressured into using separate eating utensils) alongside denial of food, being shunned, and becoming a victim of villagers' gossip:

He never wanted to come near me (sexual intercourse) again.... If he wants to come inside the room, he might come in and leave immediately or he will ask a small boy living in our compound to pick anything he wants from the room. In addition, after the problem started, I was no longer allowed to sleep on the bed; I was made to sleep

on the floor because they said I would destroy the mattress with my urine... (18 yrs, incontinent 1 yr)

My sister in-law in the same house... hated me because of VVF, which was why I was praying that it was better God, took my life...If she keeps water in a clay pot, she doesn't want me to put my "urine-soaked hands" into her pot. It was like she saw me... that I had become an object of ...no value... (19yrs, incontinent 4 yrs)

Yes, people were running away from me because before I had VVF...people deserted me...honestly, when I was healthy I was a people's person, everyone was mine... my house was always full on Sundays, like a market place.....(32yrs, incontinent 3 years)

A woman described her mother's experience of stigma by association, as her mother was prevented from cooking by the other co-wives, because of 'urine-soaked hands' from washing her laundry. As a protective measure and fear of stigmatization, a woman narrated concealing her identity with the cooperation of her husband and co-wife. Additionally, other women that claimed they did not experience stigmatization, self-stigmatized:

I do not have any problems with my neighbors or co-wife...The neighbors did not know that I had a problem... They see me healthy... Even my mother-in-law does not know, it was only my husband and my co-wife that knew I had the problem...

...(25yrs, VVF incontinent 15yrs, continence status: severe leak)

My family treated me very well, I did not go out... I did not want to go anywhere...when the condition developed... not even to church until when I got healed...( 20yrs, RVF and VVF, incontinent 2yrs,continence status: dry)

Successful repair leading to dry status eased stigma, for instance the freedom to walk about 'like a normal person' was noted by some women, making the label of 'mai yoyo' (leaker of urine) no longer apparent but to those that knew them while living with the leak.

Narrations of their friendships and continued participation in activities for ‘masu yoyon fitsari’ (leakers of urine) at the repair center could reflect their identification with the group identity. However, the most obvious unchanged identity was the spoiled identity despite successful repair. For instance, women with persisting incontinence or fertility issues post repair attributed their continuing difficulties to these unresolved issues:

Since I am still leaking... I am just managing life ... things are not as bad as before, but it could be better...I am learning to accept life as it is...it is difficult for people to change towards you knowing where you are coming from...they still treat you the way they always had done (14yrs, VVF, continent 22yrs, 7 repairs, continence status: severe leak)

#### *Identity Change and Resilience*

The identity changes triggered determination for recovery that included the use of traditional and over the counter remedies. Women referred to delays in receiving specialized care caused by ignorance of information on availability, perceived costs, and transport costs. Fistula survivors, who also escorted women, and assisted them at repair centers, provided information on care opportunities, and stimulating the hope of a cure:

My brother had taken me to one herbalist in Doma, but I didn’t get any better...no cure, till 2007... They gave me...different leaves... and asked me to be bathing with it, there is a powder that resembled saw-dust and instructed that after bathing with those leaves, I should put the saw-dust like powder into a clay pot and light a fire on it and inhale...I was on that for close to one year, without any improvement (19yrs, VVF, continent 5yrs, continence status: dry)

As the problem persist urine is pouring anyhow, sometimes I feel like instead of talking... I just go ahead, take the medicine and die...I comforted myself saying that I



am not alone. I just pray that God will help us (20 yrs, RVF and VVF, continent 12yrs, continence status: mild leak)

Woman rarely achieved a dry status after a single repair (see Table 1), but each surgery offered hope of recovery. If incontinence persisted, their determination to try again was boosted by encountering those who had achieved a dry status:

I keep wondering how some will have only one surgery and get healed, but mine is not like that...My only thought is that I too can be healed; I just want to get well ... honestly, I am in an unbearable condition, I have had 7 repairs...but as God wills the urine is still leaking. But I am still hopeful and praying that one-day God will help the doctors to have a way or wisdom for them to address my issue by God's grace. Because, as for me I have not given up hope that I will be cured... I have not lost hope; everything has its time (14yrs, VVF, incontinent 22yrs, continence status: severe leak)

Family support was crucial in getting women to the repair center and for women who needed repeated surgery, but for some, this caused issues of support fatigue. However, even when family support diminished, the women's resilience for cure remained constant:

I have gone through the problem of leaking urine for the past 22 years. I have suffered it... When the going got tough, I just told my parents to rest, I will come alone. My mother asked me, "You are going alone". I assured her I would go alone ... no problem. That is why you are seeing me here all alone (15yrs, RVF and VVF incontinent 22yrs, 7 repairs, continence status: dry)

A commonly used reference in women's story was the use of idioms to describe the temporality of the condition in deflecting or confronting stigmatization that the negative identity brought. Phrases commonly used were "I did not buy it (condition) in the market" or

“I did not go to buy the sickness with money”. Women in describing their frustration towards people’s attitude remained resilient in their desire for a cure:

...It reached a point that one day as they were talking, I opened my mouth and told them that I am the one (smelling of urine) and I got it as a result of childbirth not that I bought it from the market (18 yrs, RVF and VVF incontinent 22yrs, 7 repairs, continent status: dry)

...The way they show hatred, stigma and discrimination to me, is as if I used my money to buy it or as if I am enjoying what has happened to me. ...some of them will think I am just roaming about not looking for treatment, some will be saying why can’t I be patient and stay like that, but it is only me that knows the thing that is disturbing me (15yrs, RVF and VVF incontinent 22yrs, 7 repairs, continence status: dry)

The change of identity that impeded their social role of womanhood was a motivating factor in their continuing efforts to seek a cure and demonstrated their resilience to persist:

A grown-up woman like me, and not a baby, waking up in wet rags every day is really a problem, that is why anywhere you heard there is possibility of getting help, you have to rush there... ...(14yrs, VVF, incontinent 22yrs, 7 repairs, continence status: severe leak)

Together, our data have shown the diverse negative social identities women either enact or are assigned by the society because of developing fistula, and a seemingly positive social identity they enact through the realization that they have others who are ‘in the same boat’. Our analysis also demonstrated the ways in which these identities are contextual, fluid and can be navigated by women’s hope and resilience, leading to the quest for a permanent cure/solution.

## Discussion

The development of fistula led to life changing experiences influencing women's lives and relationships. Women narrated regression concerns around body image because of urinary incontinence, which concurs with Lupton's (2000, p. 58) 'bodily chaos of infancy' assertion. Lupton (2000, p. 53) cited body image as fundamental in how "health, illness and health care" are experienced and conceptualized, especially as it is located within "social, cultural and historical contexts", and daily experiences. Hence, the principal discourses prevalent with the sociocultural setting an individual resides in, are crucial in determining how body image is constructed (Lupton, 2000). Chronic illness that results from the disabilities of living with obstetric fistula not only results into a rupture between the individual and the social body; it makes the individual reconstruct self on various levels (Charmaz, 2000). According to the identity theorists, the self-categorization and social comparison examine the ensuing differences within a structured society (Stets & Burke, 2000). Cultural connotations of and concerning the body are important in maintaining societal views and directing social relations (Scheper-Hughes & Lock, 1987). Fistula ruptured physically and functionally the anatomy that symbolises femininity. Physically for most, the attraction to women's body was ruptured by the incontinence flow. Again, women with reproductive health difficulties experienced a rupture of sexual desire and activity. Additionally, the limited social interactions were due not only to change in woman's body but also because of failings in social responsibilities and expectation of womanhood.

The different identities portrayed signs of bodily awareness by women and attempts in reconstructing the malfunctioning and address the prevailing negative attitudes. Identity links 'self' to the existing social structures with identities demonstrating common facets of

individuals that institute the ‘what and where’ women are within their social structures (Kelly & Field, 1996, p. 245). Identity construction in response to illness is when personal identity and social processes come into conflict (Williams, 1984). Women through the process of mental dialogue drew upon past social experiences, cultural connotations and knowledge on the implications of current physical state and social existence in conceptualizing identity (Charmaz, 1983; Williams, 1984).

The different identities observed were ‘leaking’ identity, group identity (Masu yoyon fitsari - leakers of urine group), and ‘spoiled’ identity. The ‘depersonalization’ process was evidenced in developing the group identity, while ‘self-verification process was evident in developing the leaking and the spoiled identities (Stets & Burke, 2000). There appeared to be a form of temporality and a shift from one identity to another, as identity reconstruction can be transitory, and vacillating (Williams, 1984; Yoshida, 1993). The study demonstrated this transitory status as women moved from the ‘leaking’ identity, to the group identity on arrival at the repair center. The spoiled identity on the other hand, is an identity that was different to the two other identities; fixed from the development of the condition due to the rupture with societal expectations of women.

The leaking and spoiled identity illustrated the awareness of the distinction between who they were before developing fistula (self) and the new body (identity). The ‘role identity theory’ can be used to explain this – where individuals no longer view themselves as similar to others (Hogg, Terry, & White, 1995; Stets & Burke, 2000). In illness experiences, individuals’ examination of selves and identities are shaped by their society and culture (Ouellette, 1999). For some women, living with the uncontrollable flow of urine/feces and sexual and reproductive health difficulties led to loss of place in the home and community; the loss of identity as a woman/wife to being labelled as ‘spoiled’. Duties and responsibilities performed were impossible because of their ill health, and hygiene issues. This is in

consonant with the role identity theory which states that perception of difference with others was due to differences in duties (Stets & Burke, 2000). Stigmatization was commonly reported from spouse, or family/community members because of incontinence, making social integration restricted. This led to the reconstruction of self; picking up the identity of ‘leaking woman’ and/ ‘spoiled’ woman thereby triggering the psychological effects of emotions of worthlessness, vulnerability and low self-esteem (Stryker, 2004). However, this new undesirable identity changes also triggered the desire to seek a cure, signaling resilience. Making use of the illness idioms is a key feature in the narrative reconstruction as the leak was viewed as a ‘commodity’ that was not ‘purchased’; hence, it had an end date, a temporal feature. Distress as a result of the identity change can cause a change in behavior in order to change the situation and alter the inputs being received, through being more assertive or standing up for one’s right (Burke, 1991). Additionally compartmentalization and an optimistic spirit while maintaining contact with an encouraging social environment create the right condition to fight the ‘disease’(Leventhal et al., 1999), and these resonated in the data presented above.

The negative connotations of the name ‘Masu yoyon fitsari,’ – ‘leakers of urine’, were negated by a companionship identity which contributed to recovery, as the isolation felt before treatment was replaced by friendship from women with similar experiences, hence making it a positive identity. The sympathetic others in the group all share the same stigma, hence provide instruction on how to get by, provide moral support and comfort (Taylor, 1991). This new identity signaled the beginning of hope for recovery on arrival at treatment centers and contributed to their resilience when cure was delayed, as demonstrated in this study. Furthermore, group identity was equally a significant part of women’s care experiences in the redefined identity. Stets and Burke (2000) argue that self-esteem, self-efficacy, self-consistency and self-regulations are motivators of group identity. The increase

in self-worth is not only as a result of identifying with the group but also emanating from acceptance of the person as an individual in the group (Ellison, 1993). The group referred to as ‘sisterhood of suffering’ in prior studies was similarly captured in the narratives (Wall, 2002; Wall, Arrowsmith, Briggs, Browning, & Lassey, 2005) and helps to explain the bond formed by women identifying with each other’s plight. Wall (2002, p.1329) asserted this experience as an important facet of their treatment, describing it as “holistic’ medicine at its finest”; that is surgical cure together with psychological support and kindred spirit (Wall, 2002; Wall et al., 2005). This bond devoid of stigma and discrimination made their continuing stay at the center preferable to returning home for women with persisting incontinence. Some women reported hearing about availability of treatment centers from treated women and took comfort that ‘sisters’ cared, when family support became strained.

Spoiled identity professes attributes of stigma causing individual disrespect within the stereotype of what a ‘normal’ identity should be like (Goffman, 1963). Based on Goffman’s (1963) definition of spoiled identity, all the identities are described as spoiled identities. However, in this discourse, spoiled identity is presented as a specific category of identity unique to the contextual meaning women ascribed to it. In the narratives, the identities result from attributes conferred upon women as a result of fistula; as such, they can also be referred to as ‘ruptured identity’ as described by Riessman (2015) as the rupture with societal expectation of womanhood. The fistula formation caused the ‘rupture’, and in the narrative reconstruction women attempted to repair the ‘ruptures’ between body, self and the world; wherein their identity no longer lies in who they are but in the incontinence now used to describe them (Riessman, 2015; Williams, 1984). Hence, the spoiled identity reflects the consequences of the physical (smell and wetness) and reproductive health challenges. This fits within the social identity theory; an identity that originates from the framework of a structured society (Stets & Burke, 2000). This is because through social comparison process,

labels are given out to persons that differ from the ‘in group’(Stets & Burke, 2000). The negative community reaction exhibited by labelling of women and women’s perception of this, have been similarly reported in studies in Kenya and Tanzania (Lavender et al., 2016; Mselle, Moland, Evjen-Olsen, Mvungi, & Kohi, 2011). Additionally, the underlying efficacy of this bodily dysfunction can be understood with what Williams (1984) describes as the ‘social process of womanhood’; wherein the perception of this identity had been enshrined. As evidenced in the narratives in addition to the incontinence, some women are equally faced with ‘failings’ in terms of sexual and reproductive responsibilities within the prevailing sociocultural context of the study. Similarly, this difficulty has been noted in other study settings in Sub-Saharan Africa and South East Asia (Barageine et al., 2015; Engenderhealth, 201; Khisa & Nyamongo, 2012; Landry et al., 2013; Drew et al., 2016). Therefore, ‘spoiled identity’ could be viewed as a ‘double jeopardy’ for fistula survivors. Generally, the cultural representation of a woman’s body is that of a reproducer, irrespective of her intention or capacity to fulfil the function (Shildrick, 1997). The functioning of women’s lives and reproductive activities in adherence to social norms and culture was similarly reported by Hamed, Ahlberg, and Trenholm (2017).The sexual and reproductive health difficulties, contributed to family life disruptions for some women while living with fistula and after treatment. Women sought to understand the restrictions conferred on them, particularly with issues pertaining to sexual and fertility challenges. It was a crisis point as women tried to negotiate new/old relationships within a culture that defines woman’s worth by her role as a wife and successful mother. There was evidence of frustrations for those women still married who faced difficulties conceiving post fistula.

Infertility and childlessness in an African context is viewed as a grave failing on womanhood and is stigmatizing (van Balen & Bos, 2009). Among the Hausas of northern Nigeria for instance, a woman’s purpose is childbearing, with maturity to adulthood achieved

through successful delivery (Lewis Wall, 1998). Children are highly valued for the sake of perpetuity, as it is unacceptable that lineage should die, instead birth of children is preferred (Makinwa-Adebusoye, 2001). Secondary infertility is one of the injuries in the ‘obstructed labor injury complex’ that fistula development causes. Scarification in the reproductive duct caused by the fistula hinders sexual activities and hampers conception (Wall et al. 2005a).

There is a dichotomy in response to the spoiled identity between the still married and single/separated women. The single/separated women desired nothing more to do with future relationships because of the hurt experienced from rejections by their partners and the fear of fistula recurring with subsequent pregnancies. Pope et al. (2011) noted similar responses by separated women in their study. This highlights the extent of the impact of the psychological trauma faced as a result of developing fistula. Again, it suggests that the pressure to produce children exists mainly within a marital union which the single women are not exposed to, hence their reaction. Importantly, pre-marital pregnancy is frowned upon in most African cultures (Durojaiye, 2011), Nigeria inclusive, hence this can also be a reason for the single (never married) women’s responses. Interestingly, in other studies (Nigeria inclusive), married women with children were less likely to be divorced or separated because of fistula (Pope, Bangser, & Requejo, 2011; Turan, Johnson, & Polan, 2007; Umoiyoho, et al, 2011).

The contrary was observed in this study, in that two women with children before fistula formation were unable to return to their marital homes despite cure. However, the study where this occurred was in the southern part of Nigeria, where cultural practices differ to the North. Additionally, this can suggest the spoiled body image persisted in their partners’ perceptions despite cure, and further research is needed to understand this more fully.

The continued search for cure could also be linked to desires to fulfil the cultural connotations of womanhood. Generally, women with children in Nigeria are conferred a special status that reflects their role in perpetuating the lineage, hence the desire for fertility



(Ibisomi & Mudege, 2014; Wall, 1998). Prior studies report that the prominent reasons for seeking cure was for restoration of continence control and the ability to conceive to regain an identity that is valued (Khisa & Nyamongo, 2012; Mselle, Evjen-Olsen, Moland, Mvungi, & Kohi, 2012). Hence, even though some women did not achieve continence through repair, they remained resilient in seeking a cure.

In the study, sexual and fertility issues, which contributed to tension in the family, were barriers to reintegration for those women who were still married. Even though the fear of fistula recurring was evident for some women, the desire to regain reproductive capability in fulfilment of cultural norms was demonstrated in the study. This is not unique to Nigeria, as in other studies from Kenya, Tanzania, Malawi, and Bangladesh the authors also noted the difficulties with sexual intimacy and infertility that posed as challenges in fulfilling the social roles as wives and mothers (Imoto, Matsuyama, Ambauen-Berger, & Honda, 2015; Khisa & Nyamongo, 2012; Mselle et al., 2012; Yeakey, Chipeta, Taulo, & Tsui, 2009). Successful return to life meant having children, but anxiety and pain was evident from women who suffered child loss and remained childless after repairs.

Stigmatization, following fistula development, as a consequence of the change in identity are widely discussed in studies on experiences of women before and after fistula treatment, particularly with respect to its effect on relationships ( Bangser, 2006; Gebresilase, 2014; Jarvis, Richter, & Vallianatos, 2017; Khisa, Wakasiaka, McGowan, Campbell, & Lavender, 2017; Muleta, Hamlin, Fantahun, Kennedy, & Tafesse, 2008; Pope, Bangser, & Requejo, 2011; Ruder, Cheyney, & Emasu, 2018; Turan, Johnson, & Polan, 2007). Stigma is a generally known consequence of chronic illness and threatens individuals' perception of their illness experiences (Charmaz, 2000). The experiences of stigma by women in the study are a typical consequence of chronic illness conditions. The incontinence flow as the 'stigma

symbols' conveyed the 'social information' were notable / visible (wetness and smell) and instigated changes in women's social identity triggering stigmatization (Goffman, 1990).

The visibility of the stigma symbols in affecting / interfering with interactions determines the extent of stigmatization impacting on the sense of identity (Goffman, 1990). Charmaz (2000) described two types of stigma, namely enacted, and felt. Enacted stigma is act of discriminating against people based on difference, while felt stigma results from fear of discovery and shame of being different and were evident in the narratives. Women described feelings of shame, and feelings of being devalued. Goffman (1990) describes shame as a dominant possibility when an individual perceives they possess attributes considered to be defiling. The shame of loss of control over bodily function in public constitutes hygiene issues leading to movement restrictions. The high 'visibility' of the stigma symbols therefore warranted self-isolation as some participants reported. Restrictions on movements and on social interactions are coping strategies of managing felt stigma (Charmaz, 2000). Questions of 'why me?' or 'what did I do to deserve this?' were asked, and anger and sadness were demonstrable. Charmaz (2000) attributes these questionings and feelings to individuals' reactions to acceptance of the moral accountability rooted in collective representation of illness.

It is however important to note that none of the women in this study experienced total stigmatization or shunning as some forms of support appear to be present, when stigmatization was experienced. Again, research on the lived experiences of fistula survivors is typically constructed to be synonymous with "divorce, shame, isolation, stigma and cessation of sexual activity" (Yeakey et al, 2009, p. 500). In this study, not all marriages were disrupted after fistula development, and even though sexual activity was affected, it continued for some women even before treatment. This was also reported in earlier studies (Bangser, 2007; Heller & Hannig, 2017; Muleta et al., 2008; Pope et al., 2011; Women's

Dignity Project & EngenderHealth, 2006). Yeakey et al (2009, p.500) noted that marital continuity, remarriage and spousal support were normally not discussed in “research-driven constructions” of women’s “experiences of living with fistula”.

The differences in stigmatization experiences from extreme to minimal might be context related, as differences in culture and beliefs in relating with persons with debilitating conditions such as fistula could be responsible. For instance, the challenging harsh treatment reported with respect to seeking cure in a study in Uganda (Ruder, Cheyney & Emasu, 2018). According to Charmaz (2000), how, when and whether people acknowledge and behave in illness is culturally and contextually specific. Furthermore, increasing access to treatment and awareness on the availability of cure could account for differences in stigma experiences. However, it is important to reiterate here that stigmatization still exists and needs redress for women to achieve support for productive living. Women that reintegrate successfully after repairs had acceptance from both family and community (Pope et al, 2009). Recent research showed that fear of stigmatization prevented women from seeking treatment (Warren et al, 2016, Baker et al, 2017).

Women demonstrated resilience by striving to fulfil societal expectations and by dealing with the complexities of fistula; as they continually sought cure that included both traditional healers and orthodox health services, before contact with repair centers. Similarly, this health seeking behavior was reported by authors in Ghana, Kenya and Uganda (Khisa, Omoni, Nyamongo, & Spitzer, 2017; Mwini-Nyaledzigbor, Agana, & Pilkington, 2013). Further evidence of resilience involved prolonged timeframes of seeking information about treatment centers, and reporting on the supportive role of comradeship at center, as also cited in the other studies (Baker, Bellows, Bach, & Warren, 2017; Khisa et al., 2017). However, in this study, the period of seeking for cure was from one month rather than the 12 months, cited in an earlier study in the center by Wall et al. (2004). This suggests an increasing awareness and

possible access to repair services. Despite this, women's narratives cite failure to achieve full continence control and this reflects differences between surgeons and women's definitions of successful closure rates. This could be due to the fact that women have personal experience of living with fistula which is intricately linked with the social and cultural connotations within which the changes took place (Kleinman & Seemam, 2003).

### **Conclusion and Recommendations**

In conclusion, the identity and social identity theory has exposed the role of culture and society in expounding the self and identity in women's experiences of living with fistula. Following the development of fistula, negative identities of the 'leaking' and 'spoiled' identity triggered stigma issues that cause isolation and contribute to the psychological trauma. However, the women demonstrated resilience to seek cure and to exact reintegration into society. The group identity/Masu yoyon fitsari plays a prominent role in recovery, as the 'sisterhood of suffering' has a psychological healing effect as well as providing care and support to peers, particularly for those that have lost family support. Recommendations include engaging fistula survivors in a more productive targeted manner so information on repair centers is available to community members. Furthermore, because identity is socially constructed; community involvement to reduce negativity and address stigma issues is vital to support normal living. Additionally, addressing the impact of fistula on all aspects of women's lives requires further research. More specifically, fistula survivors' sexual and reproductive health issues in terms of contextualized societal roles are important during childbearing years and hence further research is needed where fistula development remains prevalent.

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Table one: Participants' characteristics pre and post fistula treatment (n =15)

Characteristics	At fistula development n (%)	Post fistula repair n(%)
Age		
< 15	1 (6.7%)	0 (0.0%)
15- 24	9 (60.0%)	1 (6.7%)
25- 34	4 (26.6%)	6 (40.0%)
35- 44	1 (6.7%)	7 (46.6%)
45- 54	0 (0.0%)	1 (6.7%)
Marital status		
Single	3 (20.0%)	3 (20.0%)
Married	12 (80.0%)	5 (33.3%)
Remarried	0 (0.0%)	2 (13.3%)
Separated	0 (0.0%)	3 (20.0%)
Divorce	0 (0.0%)	2 (13.3%)
Polygynous relationship		
Yes	0 (0.0%)	4 (26.7%)
No	15 (100.0%)	11 (73.3%)
Number of live births		
0	9 (60.0%)	12 (80.0%)
1	4 (26.7%)	2 (13.3%)
>2	2 (13.3%)	1 (6.7%)
Number of repairs		
1	NA	1 (6.7%)
2-5	NA	12 (80.0%)
>6	NA	2 (13.3%)
Continence status		
Dry	NA	7 (46.7%)
Mild	NA	6 (40.0%)
Severe	NA	2 (13.3%)