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Journey for a cure: Illness narratives of obstetric fistula survivors in North Central Nigeria

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Abstract

Obstetric fistula is a life transforming event resulting in embodied biographical disruption. Survivors suffer myriad long-term physical and emotional consequences. This paper is an account of a narrative inquiry, conducted with 15 fistula survivors in North-central, Nigeria, who described how their identities had been transformed by their condition. A narrative therapeutic approach, using Frank's 'chaos, restitution and quest' typology, was used to map their recovery narratives. 'Chaos', described by Frank as the opposite of restitution, dominated, with women losing hope of recovery. Women's shift towards 'restitution' began with treatment, but inadequate health-care access often delayed this process. In their quest narratives, women's life and identify changes enabled them to derive meaning from their experience of obstetric fistula within the context of their own lives. The findings highlight socio-structural factors raising the risk of obstetric fistula, which in turn causes biographical disruption and hampers sufferers' treatment and recovery. Rehabilitation should include income-generating skills to bring succour to survivors,

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particularly those whose incontinence persists after repairs.

KEYWORDS

biographical disruption, chaos, narrative typology, narratives, obstetric fistula, quest, restitution

INTRODUCTION

Obstetric fistula is an abnormal opening that develops between the bladder and the vagina and/or the rectum, causing urinary and/or faecal incontinence after a complicated childbirth (Bangser, 2006; Hardee et al., 2012; Wall, 2006). Once developed, obstetric fistula can leave survivors with myriad physical and psychosocial difficulties (Mselle et al., 2011; Wall, 2006). Obstetric fistula is uncommon in developed countries but remains a public health issue in Low- and Medium-Income countries (Ahmed & Tunçalp, 2015; Ngongo et al., 2020; Wall, 2006). There, the condition is compounded by poor access to maternal health services amongst women of low socioeconomic status (Bulndi et al., 2022), such that it becomes a case of structural violence (Degge et al., 2020; Wall, 2012). Structural violence describes situations where unfavourable political and economic arrangements propagate societal inequalities, with the less privileged being brought into harm's way (Farmer et al., 2006; Galtung, 1969). The suffering and sociocultural drivers linked to obstetric fistula highlight the potential benefits of exploring the voices of survivors as illness narratives (Hydén, 1997). This is especially important because in most human societies, suffering from a disease is viewed as the loss of control over the body; hence the sick person is treated as one who has lost control (Frank, 2002).

The concept of loss of control over bodily function is notable for survivors in numerous ways. Examples include physical loss of control over continence alongside other physical injuries, often referred to as the 'obstructed labour injury complex', where gynaecologic, gastrointestinal, urologic, musculoskeletal and neurologic systems are adversely affected (Arrowsmith et al., 1996, p. 9). Additionally, women with fistula report mental health dysfunctions (Goh et al., 2005; Zheng & Anderson, 2009) due to the traumatic childbirth, and/or stillbirth experiences and the effect of uncontrollable incontinence (Siddle et al., 2013). Attendant psychosocial disorders include self-isolation, stigmatisation and loss of their husband's affection, divorce and rejection by society, which compound the physical, emotional and social trauma (Ahmed & Holtz, 2007; Mselle et al., 2011; Wall, 1998). Additionally, maintaining bodily control for women suffering from the effects of fistula is problematic because the delayed access to treatment can lead to chronic illness (Khisra et al., 2017).

The primary treatment approach is surgery, the success of which depends on good surgical skills, good nursing care and management of complications, all of which are often lacking in developing countries (Abrams, 2010). Reported barriers to care include geographical inaccessibility of repair facilities, lack of funds for transportation, lack of support, fear of treatment cost, ignorance of availability of care and fear of poor quality care (Baker et al., 2017; Gebremedhin & Asefa, 2019; Mohammad, 2007). Hence, women would resort to self-management or intermittently seek care from traditional healers (Keya et al., 2018). Wherever health care is treated like a commodity that has to be purchased, it creates a barrier of access to the vulnerable in the society, thereby contributing to health inequalities (Christiansen, 2017). In the recognition that health is

a human right, the Universal Health Coverage (UHC) mandate of the United Nations stipulates that everyone should have equal access to health care whenever it is required without it causing financial hardship (WHO, 2023). However, in countries where fistula is prevalent, access to quality and affordable health care remains a huge concern (Daniyan et al., 2021). Hence, the commodification of healthcare, which is a violation of the UHC mandate, if not addressed, will hinder the work on eradicating and treating fistula cases.

Depending on the facility, various reintegration and rehabilitation services may be provided, including a combination of health education, physical therapy, social support, psychosocial counselling and income-generating skills acquisition activities (Donnelly et al., 2015; El Ayadi et al., 2020). Advocates argue that what reintegration means and what interventions facilities provide is best determined by the survivors (Abrams, 2010; Jarvis et al., 2017; Mohammad, 2007). Emasu et al. (2019) and Wall and Arrowsmith (2007) argue that successful repairs lead to the fulfilment of social roles and interactions as important factors in reintegration. Therefore, the illness narratives of rehabilitated fistula survivors, via their recovery journey, provide an insight into the various aspects of their experiences.

Illness narrative offers 'meaning, context and perspective to patient's' dilemma, providing an understanding that no other means would have given (Greenhalgh, 1999). Understanding the realities of how illness narratives are constructed through stories and language can be considered a narrative therapeutic (Sakalys, 2003). The telling of personal illness stories gives voice to the body transformed by illness (Frank, 1995). In analysing the narratives, therapeutic power is evidenced in two principal areas: through reflection on the experiences, which increases self-awareness, and via an invitation to others to learn, through telling, listening and responding (Sakalys, 2003).

Fistula development and Nigeria's health-care system

Nigeria operates a pluralistic health-care delivery system, where orthodox and traditional health delivery systems operate independently but alongside each other (FMoH, 2009). Nigeria ranked 187 out of 191 countries in the WHO overall health efficiency ranking (Tandon et al., 2000). Access to quality health care is crucial in improving health outcomes and in preventing premature deaths (GBD 2016 Healthcare Access and Quality Collaborators, 2018). The country's dismal performance was still evident in the global Health Access and Quality index assessment, where Nigeria scored 42 out of 100, thereby ranking 142 out of 195 countries (GBD 2016 Healthcare Access and Quality Collaborators, 2018). The longstanding underperformance in the country's health systems reflects Nigeria's poor health outcomes and provision of basic health services (Abubakar et al., 2022). There is a maldistribution of health workers and health service provision along rural–urban and geopolitical lines. Nigeria's health system is characterised by broad regional variations in terms of 'status, service delivery, and resource availability' (NPC & ICF, 2014, p. 5). Poor health service provision and delivery is linked to inadequate health financing and poor governance (Adeloye et al., 2017; Kress et al., 2016). The outcome of this for the country is poor maternal health indices. For instance, despite the global improvement in access to maternal health, the lifetime risk of a woman dying in Nigeria during pregnancy, childbirth or postpartum abortion is 1 in 22 compared with 1 in 4900 in a developed country (WHO, 2019). Maternal deaths are known to be the 'tip of the iceberg and maternal morbidity as the base' (Firoz et al., 2013, p. 794); for every woman that dies, 20–30 women suffer pregnancy related acute or chronic morbidities (Donnay, 2000; Firoz et al., 2013; Geller et al., 2006; Rosenfield

et al., 2007). Obstetric fistula is one of two maternal morbidities that affect the largest number of women (Hardee et al., 2012).

Fistula occurs in both the Northern and Southern regions of Nigeria. However, the Northern region has the highest prevalence of 0.5% as against 0.3% in the Southern region (NPC & ICF, 2009). The higher prevalence of fistula in the Northern region is linked to a lower utilisation of maternal health services (Galadanci et al., 2007; Mallick et al., 2016; NPC & ICF, 2009, 2014). In Nigeria, women with low educational attainment and poor socioeconomic status, living in rural locations are least likely to have their delivery assisted by Skilled Birth Attendants (Babalola & Fatusi, 2009; NPC & ICF, 2014). Poverty appears to be a common factor across the country and women that develop fistula usually come from rural communities (Emma-Echiegu et al., 2014; Ezegwui & Nwogu-Ikojo, 2005; Melah, 2007; Murphy, 1981; Nweke & Igwe, 2017; Wall et al., 2004). A primary contributing factor to the prevalence of fistula is the failure of the political and health systems to ensure equitable access to health care for all women, and this is evidence of structural violence (Degge et al., 2020; Wall, 2012). Maternal morbidities are strongly correlated with inadequate or non-existent medical care during child delivery and immediately after birth (Ashford, 2002; WHO, 2017). In countries where obstetric fistula is prevalent, Romanzi et al. (2019) noted that 'too many childbirth facilities are not only still too far to walk to, but not worth walking to at all' (p. e836).

Nigeria has 18 designated fistula repair centres, known as the National Obstetric Fistula Centres (NOFIC) where treatment is free (FMoH, 2018); these are supported by donations from agencies including the United Nations Population Fund, the United Nations Development Programme, the Fistula Foundation, Fistula Care Plus, the Ford Foundation, faith-based organisations and individuals. Outside of these facilities, women pay for fistula-repair and treatment.

The clinical goals of fistula repair surgery are primarily: (1) to close the fistula and (2) to make the woman continent and able to return to a normal and active life (de Bernis, 2007; Mohammad, 2007). There appears to be difficulty in defining what qualifies as success in term of repair (Creanga et al., 2007; Creanga & Genadry, 2007; Goh et al., 2009; Hawkins et al., 2013; Kirschner et al., 2010; Wall & Arrowsmith, 2007). Generally, success is defined by fistula closure by discharge based on tailored definitions and a subjective outcome appraisal with no regard for the impact of the procedure on the woman's quality of life (Genadry et al., 2007). However, closing the fistula does not always result in the return of urinary (and/or faecal) control. The number of repair attempts for success to be achieved varies from 1 to numerous, this depends on factors such as, early diagnosis and catheterisation (Goh & Krause, 2022). Additionally, the presence of vaginal scarring, repeat surgery and the presence of a rectovaginal fistula is reported to contribute to a higher rate of surgical failure (Goh & Krause, 2022).

The reported success rate of closure for simple fistulas is 70%–95% and for complex cases 30%–60%, and about 25%–55% of women are estimated to remain incontinent after the successful closure of the fistula (Creanga et al., 2007; Kirschner et al., 2010; Malik et al., 2017; Tayler-Smith et al., 2013; Wall, 2006). However, for women, success means the return of continence control and not the surgeon's high closure rate data (Kirschner et al., 2010) and to resume normal living (Wall & Arrowsmith, 2007). For a woman and the people around her, persistent incontinence even after the successful closure of the fistula is a failure (Abrams, 2010).

Fistula experience and illness narrative typologies

Biographical disruption, as noted by Bury (1982), disrupts social associations as well as the capacity to mobilise physical resources. Biographical disruption delineates illness as a radical 'rupture

in the fabric of everyday life, and a resulting disruption of the narratives about the future that people use to understand themselves and the trajectories of their lives' (Engman, 2019, p. 120). Biographical disruption is crucial for analysing disabling illnesses, which underlines its relevance to our study. Obstetric fistula totally disrupts women's lives, and those of their families. Modern medicine lacks a metric for existential attributes like despair, hope and grief that typically accompany illness experiences (Kleinman, 1988). Frank (1995) describes illness narratives as stories recounted through a wounded body, which have personal and social sides. These are typically reported about women with fistula as the physical and psychosocial consequences of living with the condition. Additionally, illness narratives as biographical disruption provide a medium through which to name and arrange the events in a temporal order and relate them to one's life (Sakalys, 2003). Compromised hygiene because of uncontrollable bodily secretions creates an enhanced perception of abnormality and a limitation in terms of social relations due to the need to avoid causing offence and women's feelings of shame. In this context, women's limited social interactions are not only due to bodily changes but also failings in terms of their social responsibilities and expectation of womanhood, which are more obvious for those who are married. Therefore, the focus of this study is on the biographical disruption of fistula survivors and their journeys through recovery within the Nigerian context.

In presenting this biographical disruption, Frank (1995) elucidated that illness narratives can be presented as restitution, chaos, and quest narratives. Frank (1995) added that all three narratives are told, 'alternatively, and repeatedly' in an illness experience, but that at any point in time, a single type guides the process, which may change as the illness progresses (Frank, 1995). The restitution narrative, according to Frank (1995), is the beginning and the most common among chronic illnesses, because people desire good health. The restitution narrative has a plot line of 'yesterday, I was healthy, today I am sick, but tomorrow I'll be healthy' (Frank, 1995, p. 77). Restitution is therefore a consequence of contact with 'medicine', which might be a surgical procedure or medication regime (Frank, 1995). Restitution is limited when the individual dies, or when their condition becomes chronic, or by restitution's commodification, making it financially unattainable for many (Frank, 2013).

The chaos narrative forms the opposite of restitution. In telling the chaos story, there is a lack of order; therefore, this story cuts across as a lack of 'proper' life to the listener (Frank, 2013). Chaos narratives are anxiety provoking and threatening, making restitution preferable. The teller of chaos typifies the 'wounded storyteller' (Frank, 2013). In chaos narratives, the body has been destroyed by what Frank (2013, p. 103) refers to as 'an over determination of disease and social mistreatment' and 'self-dissociation from the body' for survival. On the other hand, the quest narrative is about 'meeting the suffering heads on' by accepting and using it. The narrator passes on insights learnt from their experience to others (Frank, 2013). The beginning of the quest is the opportunity to rise up beyond what they have been, with the purpose of becoming one who has overcome it (Frank, 2013).

It is important to reiterate here that Frank's narrative typologies, although they are widely used in illness narratives in assisting listeners to hear stories, have been underutilised in studies on women's health in the developing world. Atkinson and Rubinelli (2012) argue that the use of typologies could lead to an increased risk of experiences being narrowed and homogenised into too few categories. However, a theory that reflects upon embodied experience like the narrative typologies can provide a contextual understanding of the process of sense making of the disruptive effect of obstetric fistula upon women's lives. In the current era where biomedicine no longer holds a monopoly of theories on illness, social theorising is useful in distinguishing and addressing the more psychosocial facets of the ill person beyond them being a biological

being (Armstrong, 2000). Therefore, in using Frank's (1995) typologies, this study aims to explore the transformational embodied identities caused by the biographical disruption experienced by fistula survivors, highlighting the realities of the embodied experiences of women living and coping with fistula in dealing with their social world.

RESEARCH SETTING

The study centre, Evangel Vesicovaginal Fistula (EVVF) Centre, Bingham University Teaching Hospital, Jos, Nigeria was established in 1992. It is a designated NOFIC located in the North central region and has earned a reputation for handling complicated and irreparable cases. This and its central location mean that it attracts a large volume of care-seekers from various parts of the country. To aid community reintegration, treatment and management include an option to participate in a fee-free income-generating skills acquisition programme at the centre's rehabilitation unit. The skills training options include sewing and knitting, liquid-soap production and snack making.

METHOD AND ANALYSIS

The authors' backgrounds include medical sociologist, public health researcher and nursing professor and specialists with a focus on sexual and reproductive and mental health, respectively. The research methodology took a narrative inquiry approach, which begins with experiences communicated through lived and recounted stories (Clandinin, 2007). The narrative inquiry approach, based on Dewey's (1938) theory of experience, focuses on individuals' experiences and the social, cultural and organisational narratives within which their experiences are located, shaped, communicated and performed (Clandinin & Caine, 2008).

Ethical approval for the study was provided by the University of Hull, UK and the Health Ethics Research Committee of Bingham University Teaching Hospital, Jos, Nigeria. Purposive sampling was used to identify women who fitted the inclusion criteria and were thus able to answer the research question. This meant that women who had undergone fistula repair, participated in the rehabilitation programme and gone back to live in their community for more than a year were selected. Contact was initially made with the women by phone after sourcing their phone numbers from the repair centre records. Additional participants were recruited via snowballing from the initial contacts. A total of 15 women were recruited for the study. All the participants at the time of the index pregnancy resided in a rural location (Northern Nigeria) and ranged in age between 14 and 42 years old (mean age = 21.5 years). Seven were subsistence farmers, seven were unemployed and one was a junior secondary school student (age 18 years). The women had had an average of between one to seven repair attempts. Three women were between 20 and 29 years old; nine were between 30 and 39 years old; two were between 40 and 49 years old and one was aged above 50 years. The participants had lived with fistula for the following number of months: 1–11 months ($n = 1$), 1–4 years ($n = 4$), 5–10 years ($n = 4$), 11–15 years ($n = 3$) and above 15 years ($n = 3$). Regarding how many times the participants had had repairs, 2 had undone a single repair, 11 had had between 2 and 5 and 2 had had more than 6 repairs. After the repairs, 7 experienced a dry status, while 6 and 2 had mild and severe leaks, respectively. Since treatment, all but one of the women had commenced or added sewing/knitting or petty retail trading to their means of livelihood.

TABLE 1 Frank typology and fistula survivors' narratives.

Narrative typology	Plot line	Key characteristics	Fistula survivor's narrative
Chaos	Life not getting better	Anxiety provoking Imprisoned body, loss of control Inability of medicine to control the ailment	First narrative typology Body awareness Loss of identity/identities reconstruction based on incontinence flow Ignorant of availability of cure
Restitution	'Yesterday I was healthy, today I am sick, by tomorrow I'll be healthy again'	First and general story line Brought about by medical agency Increasingly restrictive in availability	Narrative typology with contact with treatment centre Hopeful for cure with (every) repair attempts
Quest	Searching for a purpose	A sense of purpose in illness experience as a journey Opportunity to amend what was not right Tellers of the view that insight gained should be passed on	Lesson about life; chastening to make amends about life Blessing from illness-opportunity to learn skills Advocacy stances-repair advocates; SBA delivery for childbirth; women's financial autonomy through skills acquisition

Abbreviation: SBA, Skilled Birth Attendant.

The participant information sheet was read to each woman before each interview; the information provided included the right to withdraw. Consent was indicated by signature or thumb-print, after which audio-recorded data was collected using an episodic interviewing method (Flick, 2000) in the native Hausa language. The episodic interview method is a method of collecting narrative data that involves interviewing participants about situations relevant to the research question of which they have had experience (Nettleton, 1995). The interviews were conducted by the principal investigator and a research assistant in an office at the repair centre. The interviewing began with the prompt 'tell me the story of living with fistula' with the interview guide being used to provide prompts to explore in greater detail issues around the research objectives. Each participant was interviewed 2–4 times and the interviews lasted an average of 114 min. The interviews took place between February and April 2016. Furthermore, in March 2017, member checking was done with 3 of the participants to check for the accuracy of the data.

After the audio recording, transcription and translation, the data were analysed using the 2-path procedure of narrative analysis of (1) core story creation, and (2) emplotment by Emden (1998). Equally, back translation was done for a sample of the transcripts. This was a quality assurance process to ensure that accuracy was maintained in translating from the native language into English. Three main plots were identified: fistula ordeal, treatment process and returning to life. Frank's typologies were used to facilitate a deeper understanding of how the plots played out (Table 1). In fitting them under the different typologies, a detailed microanalysis of the individual text was employed. This involved the attachment of quotations, the paraphrasing of statements from the texts, the explication of the context and further abstraction in the interpretation of the constructions of experience. The analyses also involved a back-and-forth approach of listening to the recordings and reading the translated transcripts to ensure that

nuances were not lost. The authors' own professional involvement in this area was very helpful in the construction of the narratives as it provided a physiological and treatment awareness knowledge base to underpin the women's stories.

FINDINGS

Fistula chaos narrative—Living with the illness

The starting plot for the fistula narrative was the women's realisation that they must live with a condition that they had never imagined would be possible; the beginning of the biographical disruption as everyday living became a nightmare. The consequences of living with fistula permeated all spheres of their lives in addition to the physical challenge from the leak, compounded by stigmatisation for some women. Living with fistula limited their normal living, and hence caused the 'chaos', as the accounts below exemplify:

With urine pouring out without control, we came back home [from the hospital after the failed delivery]... I had this very serious pain in my legs that I could not walk, I could only crawl on my buttocks, for up to eight months...life was no longer the same... If you have VVF [Vesico vagina fistula], it restricts everything about you...

(MM, 39 years; incontinence status—severe leak)

I spent most of my time inside the house, for three years... I was being encouraged to step out and once in a while I will come out of the house... I picked the old clothes my brothers were using to go to farm that were already worn out and washed them for the rags I was using.

(GL, 30 years; incontinence status—dry)

Feelings of despair and vulnerability were evident in the women's accounts. For some, it had led to suicidal ideation and for others, drawing upon their faith for an understanding of the chaos was described:

At the initial stage of this problem, I felt all alone on the planet earth, at a point, I opened my mouth and told my elder brother that I am going to take poison and end my life. I said, "It is better for me to end my life than to live with this kind of problem"

(AL, 32 years; incontinence status—mild leak)

The thoughts that came to my mind were.... I kept thinking... and I said "ha! God, what did I do to deserve what I have become...? if it is a result of some wrongs that I have committed forgive me..., but you see it is necessary sometimes for my body to experience pain... I thank you God..."

(TL, 33 years; incontinence status—mild leak)

Thirteen of the 15 participants had had stillbirths, and this constituted another biographical disruption. In a culture that values motherhood, the loss of a child and the attendant consequence of childlessness and the stigmatisation felt worsened the chaos feeling:

I felt very sad...I was told part of the baby's body was already going rotten...I feel sad considering all the troubles I went through in carrying the pregnancy and the

delivery...I feel very sad when I see all my mates that we were pregnant at the same time with their own children...it is very painful for me...

(AL, 32 years; incontinence status—mild leak)

Persistent incontinence despite repairs worsened the women's feelings of despair and vulnerability. CL lamented, '*at that time... I was just crying... some people they just do one operation and are cured, why is my case different?*' Each failed attempt was a hope of recovery that was dashed at that point in time. Nevertheless each woman remained hopeful of a cure:

Anytime you have the surgery, you come out with the hope that that will be the end of it but up to now, I am still hopeful that by God's grace, I will be healed.

(HA, 37 years; incontinence status—severe leak)

Fistula restitution narrative—Contact with care

Restitution is brought about when the body meets with an outside agency. This could be for a medical or surgical procedure (Frank, 1995). This often signals the beginning of an end to the biographical disruption. However, the journey to recovery was not easy, due to delayed access to health care, and elongated waiting and receiving treatment periods that varied from 1 month to 15 years. While some women had no information about how to access treatment, other women, despite having information about the repair centre, experienced difficulties in going immediately for treatment. The structural factors that contributed to the development of the condition were still evident. The delays were mainly due to their inability to finance the transportation costs, even though repairs are done at no cost to patients at designated repair centres. But at that point they and their families were unaware of this fact. Some women looked beyond orthodox medicine for a cure, with those seeking care from traditional healers concluding that it was a fruitless experience. Some narrated that their choice to seek traditional care in their desperate search for a cure was due to financial difficulties:

In the first hospital, they stopped the poo but I was still leaking urine heavily...the bill was so high and we couldn't pay so we absconded in the night... I suffered many things from traditional healers, all with no results. Can you imagine I had to eat a whole cooked chicken with the feathers with just the arms cut with some concoctions in it? I even had to eat a whole head of a sheep with the hairs on it also cooked with some concoctions. ... Even the one that you use smoke, you burn some herbs and cover yourself up to inhale the smoke...all these I did...All with no solution, I was still leaking...

(RS, 38 years; incontinence status—mild leak)

Two women related using over the counter (OTC) medications purchased from a chemist [Patent Medicine store] during their quest for a cure. AS used the OTC medicines specifically to cure the leak, while MM used hers to treat the foot drop she had developed because of the fistula. Additionally, MM used traditional medicine due to her mother's belief in it, and although she did not mention this, it can be inferred that she also had some form of belief in the curative ability. Both women related their experiences:

I went to one chemist [patent medicine vendor] where a woman asks me to undress. She put her hand in my private part and told me that there are medicines that can stop the leakage, so she put some medicines together... I took all those medicines, but nothing happened...so I said ok...I just decided to continue living with it...

(AS, 52 years; incontinence status—dry)

I have taken both native and modern medicine because of the leg. It took me a long time to be able to stand up, so they were bringing both native and traditional medicine. My father didn't like native medicine, so he was the one bringing the modern medicine. My mother was the one bringing the native medicine and I was mixing the two...

(MM, 39 years; incontinence status—severe leak)

Concerning their contact with healthcare, only one woman (HA) received immediate but unsuccessful repairs at the hospital where she gave birth. Four women received referrals to other hospitals with partially successful or unsuccessful outcomes. As AL related in her narrative:

We were sent to Yola and the people there said they cannot do it, so they sent us to Maiduguri. I went to Maiduguri where I had surgery but if I sit down, the urine and stool will be pouring out as if nothing was done. I was there for six months...so I came back home...we later heard about Akwa Ibom... I went there and had surgery... the stool stopped but not the urine...there; we went up and down for months...no results...I returned home to wait for 3 years...

(AL, 32 years; incontinence status—mild leak)

The repair attempts yielded different degrees of success; to the survivors, success meant 'becoming dry'—a return to normalcy, as well as an end to the tensions of living a life defined by incontinence. Additionally, the return of continence was related by PA as follows: 'honestly...I have now returned to be a complete woman again'. Indeed, upon gaining a 'dry' status, the biographic disruption (caused by incontinence), which facilitated feelings of a loss of worth as a woman, was replaced by the feeling of being a 'restored' woman. The ability to 'feel' again signalled the return of control over the involuntary urine flow. For some, this control was instrumental to a change of status from a life of avoiding people to that of increased social interactions:

The evidence is that even when I am deeply asleep, I can feel it when my bladder is full. Before my last surgery, that wasn't the case...I go to farm, I go to conference and spend the night there in the midst of people without any problem.

(GL, 30 years; incontinence status—dry)

Treatment included optional participation in a rehabilitation programme that involved income-generating skills training. Reflections on the benefits of acquiring the income-generating skills varied due to individual circumstances:

...Everyone in our house is into steaming and milling rice which is a very difficult job that I cannot do now, so I say thank you to God... that God has blessed me with

something easier in this sewing....so even if I am in pains, I can still sit down and do my sewing...

(MM, 39 years; incontinence status-severe leak)

Restitution came with contact with medical care and rehabilitation, which helped to rebuild the women's disrupted biographies to what they were before, or for some, better than they were before the problem started. For those with persistent incontinence, it provided an outlet of hope over their hidden frustration due to delayed recovery.

Fistula quest narratives—Providing answers

A quest narrative is the most distinctive voice for the ill person, as it seeks to pass insights on with the experience. The quest narratives on the ordeal of living and coping with the condition included a reassessment of their personal lives after experiencing fistula and the changes that contact with treatment bought. The women provided insights that included encouraging and motivating others during treatment or rehabilitation:

Anytime I come and meet women on training here, (because I use to enter the centre when I come), I use to encourage them to put in their best. If I see women looking or doing something different when the trainer is trying to show them something, I use to challenge them saying, "kai"! [an exclamation of indignation] during our time, we did not have people to teach us all that you are opportune to learn now, for it was only one woman who was teaching us what she knew...

(MM, 39 years; incontinence status—Severe leak)

Another quest narrative was related to the change of outlook in relating to the opposite sex for those who had never married. These women spoke of encouraging younger women to be more responsible and focused on what would contribute to their future. On the other hand, the women who were married with children returned to their partners for the purpose of seeking better futures for their children, despite being rejected after their recovery.

There was a girl that was staying with me at home, and she had one boyfriend. I told her that that is not how to do it. Now you are following boyfriend before you know it, you will follow him or may become pregnant for him. Early marriage has its own problem. She was just in Junior Secondary 3 (approximate age: 13 years) so I told her to concentrate on her studies since her father is paying her school fees...you better face your studies.....when they whistle at you.....you better not listen to them... I have started talking with girls about it even before I start teaching.

(GL, 30 years; incontinence status-dry)

It is not easy for a woman to be married and then go back and stay with her parents... The problems I am facing now had to do with children because my husband is not taking proper care of the children and where I am now, I don't have enough to meet all their needs and I keep thinking that my children will accuse me saying it was because I did not go to school that is why I did not put them in school so I am

praying that God will open doors for me because this is no time for staying without education.

(TL, 33 years; incontinence status—mild leak)

The new lease of life and understanding of life highlighted in the quest narratives included the importance of rehabilitation for financial empowerment. Additionally, the reflection included advocating for women's financial empowerment:

I want to advise women to come out and learn a trade. Every woman should come forward... You don't have to look up to your husband for every little thing...

(LV, 38 years; incontinence status—mild leak)

Another turning point was the women's awareness of the causes and treatment of fistula, with women actively creating awareness and information about how to access fistula treatment in their community. One woman argued for the need to abolish traditional birthing practices that do not permit women to utilise maternity services, because of their partners' and the older generation's objections.

There are a lot of women who have this problem but our approach (that is me and my husband) is, when we come across such women, we give them awareness. Sometimes my husband will even escort them to this place so they can access treatment.

(PA, 37 years; incontinence status—dry)

I will beg our parents to always listen and do what the doctor says. If pregnancy occurs, the husband and parents should not stop their daughter from going to the hospital where her health and that of her baby will be checked. They should stop all those traditions... That is what is responsible for all the difficulties I have gone and I am still going through. That is what I have to close with... My plea is that people should visit hospitals so that doctors will advise appropriately; they should also not allow women go into labour at home because it is not good. That long labour is what is responsible for my problems... That is all I have to say in closing...

(HA, 37 years; incontinence status—severe leak)

The quest in the narratives symbolised a turning point, moving on from the past to the future, that challenged norms and provided answers not only for themselves but for other women. In identifying a cause of their biographical disruption, the women became advocates against harmful traditional childbirth practices.

DISCUSSION

The narratives of the fistula survivors in the sense-making of their recovery journeys illustrated their varied and complex interpretations within their daily social living. As observed in this study, Frank's narrative typologies have highlighted the voices of an illness experience that medicine could not have encapsulated. The description of 'biographically uncertain terrain' noted by Williams (2000, p. 42) exemplifies the first narrative typology of chaos. Chaos narratives are typical narratives of loss of control, which Frank describes as being carried along 'without control,

by life's fundamental contingency' (Frank, 1995, p. 102); in this case, a life defined by incontinence, which marked the beginning of the women's biographical disruption. Frank (1995) notes that the chaos narrative sometimes triggers an opening up to faith for those who are so inclined. Viewed as a moral narrative (Bury, 2001), in seeking the good out of the 'badness of illness', this is construed to be a chastising period to be better persons. Though this is beyond the scope of this study, in telling their chaos stories, the contributions of traditional belief/practices to the development of the condition were mentioned by some participants. However, even though an understanding of the cultural influences is important, it is crucial to avoid playing the game of 'cultural pathology' as this has become a diversionary distraction from addressing the structural violence that leads to fistula (Heller & Hannig, 2017). In this study, the involvement of traditional practices was due to ignorance and financial difficulties in securing care. Fistula is entirely a preventable tragedy with the provision of emergency obstetric care. Its prevalence in Low- and Middle-Income countries is a reminder of the failure of health and social systems to protect vulnerable women and girls and an indicator of gross inequities and global inequalities (Arrowsmith et al., 2020; Wall, 2006).

In contrast to Frank's (1995) sequencing of the narrative typologies, where restitution is the beginning, this was not the case in this study. In Nigeria, access to health care is slow in comparison to western cultures, where Frank's illness narratives are situated, and this could explain the difference in sequencing. Furthermore, the women were mostly unaware of what type of ailment it was, as most had never heard about it, and thought there was no cure. Health-seeking behaviour is more influenced by networks of interacting explanatory factors in developing countries than in developed countries (Kroeger, 1983). The most significant enabling factor is geographical accessibility, while the other enabling factors are acceptable patient–doctor communication, quality of service and cost and fees (Kroeger, 1983). The more chronic the condition, the more likely it is that patients will resort to different avenues of care, including traditional medicines (Kroeger, 1983). This contrasts with health seeking behaviours in Western societies. Studies on health seeking behaviours for obstetric fistula treatment have identified poor health systems and economic factors as significant influencers (Chimamise et al., 2021; Gebremedhin & Asefa, 2019; Khisa et al., 2017). The chaos narrative, which Frank describes as the opposite of restitution, was the first and most common in this study. The women lived in chaos due to the commodification of restitution. This further evidence the issue of health inequity that is prevalent in Nigeria and highlights a violation of the UHC mandate, which stipulates that no one should face financial hardship in the process of accessing healthcare.

In overcoming the hurdle of access, restitution was a triumph for medical practice for the women that had regained a total dry status. Frank (2013) described recovery after a medical intervention as a triumph for medicine. In this context the dry status, is a measure of successful repair from the survivors' perspectives. This victory culminated in the restoration of lost dignity as a woman, and the return of self-confidence and self-worth. The limitation of restitution was also present (Frank, 2013). Frank noted this as failure for a full recovery despite medical interventions. In our study, women with persistent incontinence, despite their repair, could fit into this category. Additionally, such women appeared to fit into the typical chaos narrative of Frank and appeared to be speaking with both the restitution and chaos voices. For them, the beginning, middle and end, the past and the future were all blurred lines of ambiguity, as described by Riessman (2015). For a woman and the people around her, persistent incontinence even after the successful closure of a fistula is a failure (Abrams, 2010). In this study, repeated visits to the repair centre in the hope of a cure were observed. However, in the face of the narratives of repeated repairs this evidences resilience; an action directed towards overcoming the adversity (Kralik et al., 2006) of living with incontinence.

The rehabilitation programme can be considered part of the restitution story, as the women's income-generating skills facilitated the transformation of their identity. For women still incontinent, access to funds was a coping mechanism, given that it created unlimited access to treatment travel expenses. This restitution story is not a part of Frank's description, but in the context of fistula, this aspect of a sustained hope of recovery is vital. Survivors who are considered incurable should be in the front row for assistance through social reintegration and rehabilitation service facilities (UNFPA, 2020). In the light of our findings, repairing the biographical disruption is in line with Williams' (2000) practical response of a 'mobilisation of resources' (p. 43).

In the quest narrative, the teller takes hold of the suffering, accepting the ill health and making a meaning out of it. In this instance, the biographical disruption had a positive consequence (Nettleton, 1995). The changes in the women's lives and identity were a platform for gaining meaning from their illness experiences within the context of their own life experiences (Hydén, 1997). The meanings were influenced by the 'historical, cultural, social and situational contexts' (Charmaz, 2000, p. 282). Hence, seeing life in the light of the illness, the narrative was a turning point and an opportunity for reflection. Frank (1995) noted that this is a demonstration of reminiscence, cohesion and motivation.

Additionally, in the quest narratives, some women proffered various suggestions from their experiences. These suggestions were represented as an advocacy stance and included promoting awareness of surgical repairs for women living with fistula in the community. Frank noted that involvement in-patient advocacy is an example of a quest narrative (Frank, 1995). Women that had benefitted from the skills acquisition lauded the rehabilitation programme and strongly believed that women should take advantage of acquiring an income-generating skill to improve the quality of their lives. The construction of deeper meanings that lead to a shift to a different identity can occur after chronic illness (Charmaz, 2000). Another noteworthy one was the women's advocacy for the abolition of cultural practices that do not support the utilisation of maternal health services by pregnant women for childbirth. Advocacy provides a voice of those who have weathered their illness (Charmaz, 2000, p. 288). Hence, it is important to encourage and provide more opportunities for survivors to serve as ambassadors in their communities, placing them in the forefront to mobilise changes when women still face gender inequity.

Some of the strengths and limitations of this study are worth mentioning. Narrative approaches are excellent at exploring the life stories of individuals over time; they allow people to describe important events in their lives to researchers who can then construct meaningful conceptualisations of those experiences—contrasting and comparing them with the stories of others, to provide an overarching narrative structure (Toledano & Anderson, 2020). However, the subjective nature of individuals' accounts is a limitation if the researcher has little experience of the phenomena under study and can supply context to the stories of participants (Mueller, 2019). In this study, the researchers experience and immersion in the fistula rehabilitation process mitigated against that possibility.

For this study, Frank's typology provided a framework to categorise the women's narratives. However, some aspects of the survivors' experiences transcended Franks' description. Engman (2019) argues that experience of illness, should be about ways in which elements of the condition interact with individuals' embodied orientation with their world, and what they have learnt from this. Class, age, gender and ethnicity are dimensions of biographical disruption that remain emphasised and poorly researched (Williams, 2000), and this study's sociocultural context is different from that of the illness experiences in Frank's typologies. Our study provides an insight into a totally different setting, and in doing so, contributes to the body of evidence about how socioeconomic differences shape illness experiences and their recounting.

CONCLUSION

We believe this study is the first of its kind to employ Frank's typology to explore and analyse illness narratives of obstetric fistula survivors in Nigeria. Accordingly, in line with Frank's (1995) stance, this study advocates a clinical ethic and care that is multi-vocal, where nonmedical voices can be heard. The women's narratives highlight the contribution of rehabilitation programmes to providing income-generating skills, particularly for women with persistent incontinence. The study also highlights the need for national resources to be mobilised to fund fistula management, particularly to build the capacity of locally trained skilled fistula repair surgeons. The narrative typologies provide an insight into the life-changing impact of obstetric fistula and expose the chaotic socioeconomic and political systems that perpetuate the problem (Degge et al., 2020; Wall, 2012). The prevalence of obstetric fistula in the 21st century is unacceptable. Hence, this is a call for all policymakers and governments to provide equitable access to maternal services, which is a target of the Sustainable Development Goal of improved health and wellbeing for all.

AUTHOR CONTRIBUTIONS

Hannah M. Degge: Conceptualization (equal); data curation (equal); formal analysis (equal); methodology (equal); writing—original draft (equal); writing—review & editing (equal). **Mary Laurensen:** Conceptualization (supporting); supervision (supporting); writing—review & editing (supporting). **Emeka W. Dumbili:** Formal analysis (supporting); writing—review & editing (supporting). **Heidi Saxby:** Writing—review & editing (supporting). **Mark Hayter:** Conceptualization (supporting); supervision (lead); writing—review & editing (supporting).

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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