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Absence and Reliance

Liberian women's experiences of living with Vaginal Fistulas

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Abstract

Childbirth entails considerable risk in developing countries. A prolonged labour process can cause the woman sustained injuries and lead to the death of the unborn child. Many women in Africa suffer from vaginal fistulas, causing a constant leakage of urine and/ or faeces. The aim of this study was to explore and describe women's experiences of living with fistulas and how it affects their daily social life. An ethnographic inspired design involving observation, group- and individual conversations, was carried out at a gynaecological ward at a rural hospital in Liberia with fourteen women. The reflexive analysis during fieldwork revealed two main themes in the women's experiences; absence and reliance. The result demonstrate that the women felt a loss of control over a perceived traumatic birth, loss of the dead child, loss of status as a woman and wife and loss of social fellowship. They also felt a loss of self-confidence. In contrast, the women relied on their belief and trust in God.

Keywords:

Absence, Africa, Ethnography, Fistula, Prolonged labour, Obstetric fistula, Reliance

Background

Millions of women suffer from serious injury, infection, disability or other health problems as a result of pregnancy and giving birth (WHO, 2010). A commonly occurring health problem is the vaginal fistula, which can arise after a prolonged labour. When the baby's head presses against the woman's pelvis for a prolonged period the risk increases of necrosis in the fragile tissue of the pelvis (Wall, 2006). The most common fistula form is the vesicovaginal fistula (VVF), which forms between the bladder and the urethra. Another fistula form is between the vagina and the rectum, known as a rectovaginal fistula (RVF). The consequences of a fistula are that the woman is unable to control her bladder and/or bowels, and leaks urine and/or faeces (Hancock, 2005; Holme, Breen & MacArthur, 2007). Many women in Sub Sahara live with VVF and/or RVF (Miller, Lester, Webster & Cowan, 2005). The number of unrecorded cases is likely to be large, since the statistics are based on the women who have sought help at a hospital (Cook, Dickens & Syed, 2004; Stanston, Holtz och Ahmed, 2007).

The risk of prolonged labour is larger in early pregnancy for a girl whose pelvis is not fully developed. Underweight and undernourishment are also risk factors if the pelvis is not fully formed (Holme, Breen & MacArthur, 2007; Tsui, Creanga & Ahmed, 2007; Wall, 2006). A study conducted in Nigeria, based on 899 women with VVF, shows an average age at the time of marriage being 15½ years. The women were short in stature, under 150 cm, and had an average weight of 43.6 kg (Wall, Karshima, Kirschner & Arrowsmith, 2004). The same study draws also attention to traditional birth attendants (TBA), who might attempt to widen the delivery passage for the baby, which in turn can cause damage to the pelvic floor. In a study from Ethiopia, based on 1210 women with VVF, 50% had developed the fistula between the ages of 13 and 20. For many of them (55%) this had occurred in conjunction with their first pregnancy (Muleta, 1997). Female circumcision can also lead to prolonged labour (Berggren & Franck, 2008), as well as sexual violence (Cook, Dickens & Syed, 2004). Women in war

zones and refugee camps are particularly at risk of being subjected to sexual brutality. Sexual violence as a means of waging war has been reported in countries, such as Sierra Leone, Liberia and the Democratic Republic of the Congo (Longombe, Claude & Ruminjo, 2008). Another risk factor for prolonged labour for a pregnant woman is the problem of a long journey to the maternity clinic (Zheng & Anderson, 2009). In addition certain African cultures accept the belief that women undergo prolonged labour as a form of punishment (Wall, 2006; Ahmed & Holtz, 2007).

The physical consequences for women who have undergone a prolonged labour can be wide-ranging. Because the woman has had constant pressure on the sacral nerve over a long period nerve damage can be sustained (Hancock, 2005). In a study, carried out in Zambia, 43% of the women with VVF had difficulty with walking. Other physical consequences included vaginal stenosis and bladder stones (Holme, Breen & MacArthur, 2007). Further, Ahmed and Holtz, (2007) pointed out that up to 80 % of women with VVF will develop skin problems as a result of a constant urine and/or faeces leakage, often entailing fungal infection.

Studies of the social consequences for women with a vaginal fistula describe how the problems of hygiene and bad odour affect the women's social life (Ojanuga, 1994; Cook, Dickens & Syed, 2004; Miller, Lester, Webster & Cowan 2005; Ahmed & Holtz, 2007; 2009; Muleta, Hamlin, Fantahun, Kennedy & Tefesse, 2008; Roush 2009). These studies described that the women were not allowed to prepare the family's food. They loosed their status within the family. They, more often than other women, were deserted by their husbands. A man who supports his wife often meets opposition from within his family. However, the studies showed that a husband was more likely to stay with the woman if the child survived childbirth. The above studies further demonstrated that women suffer from low self-esteem. They felt depressed and lived in a constant state of anxiety. The sorrow and bitterness they felt in life was exacerbated by the fact that their child was stillborn.

Other studies showed that surgical treatment improved the conditions for the women living with VVF/RVF. Such treatment involves repairing the soft tissue damage caused by the urinary and /or faecal incontinence and restoring normal bodily function (Browning, Fantahun and Goh, 2007; Muleta, Hamlin, Fantahun, Kennedy & Tefesse, 2008). One study from Ethiopia (Browning & Menber, 2008) showed that the majority of the women considered their lives to have improved since their treatment as they were more socially active. Moreover one third of the women had had sexual relationships and not experienced any vaginal pain. Complications after surgical treatment arose when women had resumed sexual relations too early, had engaged in hard physical work, travelled long distances on bumpy roads or walked long distances, e.g. to fetch water (Wall, Arrowsmith, Briggs, Browning & Lassey, 2005). The above studies investigated women's conditions with a vaginal fistula (VVF or RVF) before and after surgical treatment. However, as far as the authors know, no study has listened to the women's narrative experiences of living with a vaginal fistula. The present study aimed to explore and describe Liberian women's narrative experiences of living with VVF while waiting on a hospital ward to undergo surgical treatment.

Methodology

An ethnographic inspired design was used for the study (Crang & Cook, 2007). This design involved to participate at a hospital ward together with women who had been admitted for surgical treatment because of VVF. Permission for the study was granted by the management board of a rural hospital in Liberia. Ethical considerations were based on the principles of research ethics (Swedish Research Council, 2002).

The setting – A Rural hospital in Liberia

Liberia in West Africa has about 3,5 million inhabitants. The official language is English, with 18 different local language groups. Religious affiliation is for the most part Christian (85, 5%) . Muslims make up 12,2 % of the population, and in addition there are native religions (www.state.gov). The Human Development Index was 162 in 2010, and life expectancy was 59,1 years. The average duration of schooling was 3, 9 years, and the maternal mortality rate was 1200 of 100 000 live births (Human Development Report, 2010). Liberia has for many years suffered from civil war with a subsequent lack of health and medical care. Since August 2003 the country has become more stable.

The rural hospital is situated approximately 3 hours by road from the capital, Monrovia. The hospital is the central point for the village, and is run in conjunction with the Ministry of Health, and the Lutheran and the Anglican Churches in Liberia. The hospital also houses a nursing school. Patients are taken in regardless of religious affiliation. In addition to an extensive outpatient organisation, the hospital has three main departments; medical/surgical, obstetrics/gynaecology and a children' s ward. Electricity is supplied by a generator, providing power by night and day and making surgical operations possible. When this present study was conducted, a collaborative project with Swedish surgeons providing fistula treatment at the hospital was in progress. The free surgical treatment of women with VVF was advertised on the local radio station. The information was also passed orally around the local villages.

Women arriving on the gynaecological ward received verbal information about the study and that a researcher would follow the women' s progress and arrange talks with them, both in groups and individually, as well as arrange some social activities. They were informed that their participation was completely voluntary and in no way linked to access to the surgical treatment they were about to receive. They were further informed that they could opt out, choose not to

reply or leave out any question asked by the researcher. A conscious effort to uphold the women's right to privacy was made whilst the women were on the ward (Burns & Grove 2001).

Data collection

Fourteen women participated in the data collection. Naturalistic observations, group conversations and individual interviews were the sources of the information collected (Crang & Cook, 2007). To ascertain the women's experiences of living with VVF it was important for the participant researcher (XX) to interact and to become involved culturally at the ward (Gray, 2003; Crang & Cook, 2007). Handicraft activities were organised and evenings were spent with the women singing and dancing. Gathering together and taking part in communal activities created a sense of fellowship. Three student nurses who acted as interpreters also took part in the activities. They were told that confidentiality applied outside the groups.

The women were observed in their activities and conversations on the ward from their admittance to examination, and during and after their surgical treatment, with field notes being taken in line with the aim of the study. Group conversations were conducted with a total of 11 women broken down into four groups, according to their language group (three groups of three women and one group of two women). The group conversations followed a semistructured guide which aimed to capture the women's experiences of living with a vaginal fistula/VVF in their family and community. Some of the women were more shy and quieter than the others, but were nevertheless interested in each other's experiences. The women's interaction during the group sessions became valuable because they inspired each other to reflect (Morgan, 1997). The group sessions were tape-recorded. Individual interviews, at which notes were taken, were conducted with three other women. Three student nurses translated into English at both the group sessions and the individual interviews. They were told the importance of translating as literally as possible. The individual interviews were coded 1-3, and the group sessions A-D.

Reflexivity and Analysis

Reflexivity during fieldwork, the collection of data, containing field notes and transcriptions, and the authors pre-understanding was of importance during the analysis aimed at capturing the women's experiences (Crang & Cook, 2007). Two of the authors (XX and NN) have earlier experiences of nursing in African cultures. During the fieldwork the participating researcher made a tentative understanding of the women's experiences which emerged two main themes. The first theme had a pervading negative tenor conveying the women's sense of *absence* of varying character in their daily lives. The other theme running through the women's narratives told a sense of *reliance* in their daily existence. In the further analysis a series of sensitive meaning units in the transcribed texts from the women's narrative were coded and developed into categories of experiences beyond the themes absence and reliance (Dahlgren, Emmelin & Winkvist, 2004; Crang & Cook, 2007). The result is reported as a narrative description of the women's experiences.

Result

The age of the women in the study (n=14) was between 20 and 55 years old. They had been married at an early age. Their average height was 151.5 cm and their average weight was 48.9 kg. None of them could read or write and all of them only spoke their local language. Some of them had children. During the time spent on the gynaecological ward undergoing surgical treatment a sense of social fellowship formed amongst the women. They prepared meals together. They interacted in handicraft activities, song and dance. They cared for each other after the surgical treatment when necessary.

The women had all contracted their VVF as a result of prolonged labour. They had been labouring between 1 and 7 days before the delivery was complete. The labour pains had begun at home, and after a few days some of them had been taken to hospital. Some said that they were unconscious at that time. They had had fistula problems and leaked urine for periods from 2 weeks to up to 22 years.

From the women's experiences the theme of *absence* emerged as the common binding character of how life had changed after contracting VVF. Their experiences encompassed a loss of control during delivery, the loss of their child, of their status within the family, of social fellowship and of their self-esteem. Another emerging theme that unified the women's experiences was the *reliance* they gained from their belief in God, which in turn gave them reassurance and hope for the future.

Absence

Loss of Control

The ongoing war in Liberia meant that the women lived with the fear that there was nowhere they can give birth in safety. They felt isolated and dared not stay in their village for fear that the rebel soldiers would come. They moved out into the bush: *"During the war there were almost no midwives around, so when I started my labour the midwives who were there took me into the bush" (D).*

The women described their delivery as a feeling of loss of control over their bodies, accompanied by a sense of fear, pain and feeling threatened by their surroundings. Some were bound hand and foot and other women tried to induce the birth of the child. *"They forced me to the ground, pressed my shoulders back, put a spoon in my mouth and tried to push the baby out" (I).* Another woman recounted: *"I remember I was suffering. I was hanging onto somebody's shoulder so they could push the baby out...they scared me and said you don't want to have this baby....they scared me" (C).* The women further used expressions such as they *"put their hands inside me and played with my private parts"* to encourage the labour to begin and to force the baby to come out: *"...they stretched my vagina, forced it up so it became swollen, and very painful, really painful" (Woman 1).* For one or two of the women the experience was so painful that they were almost unable to describe what they had been through when crying. A fistula was something new the women had never heard of before, neither they had met other women suffering from fistula problems. When they discovered that they were leaking urine and had lost control over their bodies they had feelings of shame and guilt: *"I knew nothing of this illness. I became afraid and I did not know what had happened to me. I was worried. I*

though I was the only one.” (A). Some women explained that they felt no longer of any use and felt worthless: “I cried and said nobody want to be with me, I’m worthless now” (C).

Loss of a newborn baby

As a result of the prolonged labour that had caused the fistula problem several of the women had lost their child. The women became very emotional when they spoke of their loss and their pain, and of missing their child. Other women were childless because their injury had made it impossible for them to bear any more children. Some women had experienced the loss of more children before and after they incurred their injury. The women who were childless expressed great sorrow: *“I went through a lot of pain and at the end of the day I did not hold a child in my arms” (Woman 1), and: “I started to ask about the child and they said the child was not alive when born. I felt bad, I cried.” (D.)*

Loss of status as a woman and a wife

The women described having been abandoned as wives: *“When I became sick my husband left me.”(A).* The women told they accepted that the men did not want to have sexual relations but continued to provide for them: *“I can’t worry about that. The only thing I need is that the man finds food for me to eat.” (B).* The women’s husbands sought out other women, because their wives could not give them children or because they suffered from bad odour: *“My husband left because of the peeing problem. He left and now he is married to another woman. I felt very bad.” (3.)* Another woman said: *“I could not give birth again, so he said he would look for another woman to give him a child” (A).* The husbands were more likely to stay in the relationship if there were children in the family. When the men stayed with their wives it often happened that they had “secret girlfriends”, which either the wife or the man had chosen: *“He has a girlfriend, but they are hiding it from me” (A).* The women felt forced into allowing their husbands the freedom to find a girlfriend, because of the “peeing problem”: *“I feel sad. I can’t say anything about it (that my husband has a girlfriend). My life is important, he supports me, so I give him his freedom” (A).* When the women spoke about finding a new woman for their husband, they reasoned that it was better if the wife found a new woman for her husband. In that way the wife still had control of the situation, instead of the husband finding a new

woman without her knowing about it. By finding a new woman for her husband the woman could stay in the family: *"We can never have sex my husband and me. I looked for another girl to give to my husband. I looked for a girlfriend for my husband because the man has feelings, and I will do that for him"* (B). Some women longed to meet a new man to be close to, but felt themselves to be worthless: *"I looked for someone, but because of my condition no one wanted to be with me. No one will keep me. I can't get anyone"* (C).

Loss of social fellowship

The women experienced the loss of the social life they had before they were afflicted with the fistula. They were cut off from society because they leaked urine, had bad odour and "wet skirts". When they talked with each other, it emerged that some had chosen to be alone and isolated themselves, while other been ostracized by friends and family members they had once mixed with. This cutting off from social fellowship was manifested by the woman being laughed at, teased and criticised.

When choosing to isolate themselves it meant that the women did not go out and mix with other people. Because of their "peeing problem" they did not want to meet other people. Some had a nerve damage which meant that they found walking difficult, and therefore chose to cut themselves off: *"I don't want anybody to see me because of this condition"* (C). One woman said that she often went out at night into the bush looking for food. She did this so that no-one could see her and so that she would not be a burden to the other family members: *"I go out into the bush at night to find things to eat. No one will see me"* (C). Several women stated that after undergoing the prolonged labour they found it difficult to walk or to move normally. They described it as one leg not following as it should. This meant that they isolated themselves, having difficulty carrying out their personal hygiene and work around the home: *"My foot was not good. I could not walk okay afterwards."* (B).

The women experienced emotional isolation, without friends or family to talk to, and because they leaked urine and faeces they had to wash their clothes very often. A large part of their working day was taken up by fetching water, washing and drying clothes. The pure physical work of managing all the washing of clothes was hard enough, but the leaking of urine also gave them a feeling of

insecurity, despite many women trying to hide their problem by wearing cloth bandages all the time: *"I was afraid that I would leak. I kept washing and I was embarrassed because I was wet."* (Woman Group A).

The women described people isolating them by making fun of them, whispering about them leaking urine, and having a bad odour, and people not wanting to be near them: *"Since I became sick they abandoned me and I feel ashamed to go out" "My friends ...they don't want to come near me, and when they do they smell the bad odour...they criticize me"* (Woman Group B). Women who were once their friends laughed at them, made fun of them, whispered about them and joked about them: *"They said a lot of things about me and laughed. People said that I peed on myself"* (Woman 2). Some of the women told that they no longer went to church because it created such a social problem, partly because they were afraid that they would leak urine and partly because they were embarrassed by the bad odour that they carried: *"I went to church and after the service when I walked down the aisle my whole lap was wet, and people started looking at me from behind. So I don't go to church any more,.. I've stopped because I feel so ashamed"* (B).

Loss of self-esteem

The women were not only emotionally isolated, they also experienced feelings of depression: *"Before this problem I had a good life, now I am depressed"* (2). The women talked of feelings of shame; shame because their wet clothes, the urine that ran down their legs and the bad odour they carried. Shame was also felt because of their fear of not knowing what was happening to their bodies. Some of the women had been told that they had sinned and that this was why they had been afflicted with VVF. Before they came to the hospital a number of them had not spoken to anyone else about their "peeing problem". *"Until now I have never talked about it... I'm sort of ashamed"* (B).

Reliance

Belief in God

In the evenings at the ward the women sang songs of praise in their various dialects and danced. They sang of their faith in God and the strength this gave them in life. They prayed both with and for each other. The women described their faith in God as important in the situation they found themselves in: *"I felt bad , but I relied on God"* (A). The women showed a belief that their God would heal their bodies, and asked in their prayers that this would be so. Their prayers also asked that God would work through the nurses and doctors, and the resources that the hospital provided to heal their bodies.

Trust and hopefulness

The women trusted the God they believed in to take care of them: *"When my husband left me I gave myself over to God"* (C). The women described their trust in God as a feeling of 'being loved despite everything'. When discussing the future they talked of their worries of how life would turn out for them. It was their trust in God that gave them hope for the future. *"I just pray that God will free me from this condition"*(C). Their hope for the future concerned both the surgical treatment they were about to undergo and the opportunity to travel home to their village and family. Their trust and hope for the future was borne out in their songs of praise: *"My Lord is working for me I will not worry-O"*.

Discussion

Following the daily life of the women on the ward gave an understanding of their lives and their experiences. The social fellowship, created on the ward, probably made them more prepared to talk about their experiences, beliefs and thoughts on life. The women had learnt on the ward that they had contracted their vaginal fistula as a result of a prolonged labour process. Some women had forgotten the actual delivery, while others described the pain, suffering, loss of control and feeling maltreated. They spoke of external pressure being applied to their bodies during labour.

Such threatening behaviour and violence from birth attendants has also been described by Wall et al., (2004).

A common occurrence after a prolonged labour was losing the baby (Muleta, 1997). The women in this present study described their pain and sorrow over the death of their child. Being afflicted by and having to live with VVF further led to the women losing their status. The fact that they had not given birth to a living child was a contributing condition (Ojanuga, 1994). Roush (2009) emphasised that in many cultures a woman gains her status by having a baby. If there are children the likelihood that the woman will be able to stay at home increases, and therefore she will be provided for. If she is abandoned by her husband, she will become dependent on others in the community and therefore becomes a burden. Those who are not provided for may be forced to go out and beg, which was described by Cook, Dickens and Syed (2004).

A woman's duty to satisfy her husband was described earlier by Roush (2009), but the fact that the women, as in this present study, accepted that their husbands found new wives or had sexual relations with girlfriends has not been earlier described. The women spoke of finding girlfriends for their husbands to satisfy their demands and needs.

Living alone, isolated and without social fellowship was the most concerning element for these women. Some women in this present study said they had chosen to live alone and cut themselves off from society. It is quite possible that they chose to isolate themselves, in order to avoid being ostracized by others. Ojanuga (1994), Ahmed & Holtz, (2007), Miller et al, (2005), Tsui et al. (2007) and Ahmed & Holtz (2007) also describe women who choose to be alone through shame and guilt. The women lived with the problem of constantly soiling their clothes, finding it hard to keep provided with water, having to suffer bad odour and contracting illnesses because of urine being in constant contact with their skin. Other fellows pointed at them, whispered and gossiped, and laughed at them. Having to live with that led to the women withdrawing themselves from society (Roush, 2009). A number of the women in the present study also longed to meet a new man. Browning and Member (2008), however, argued that single women, who had undergone

fistula surgery, for the most part continued to live alone, but had more social contact than before the surgery.

Ojanuga (1994) and Muleta et al. (2008) highlighted the fact that women with VVF often had low self-esteem. A number of the women involved in the present study were withdrawn, shy and did not say much, whilst at the same time they were interested in the experiences of others. They had lived in fear of leaking urine. They were now able to reflect and talk with others how they missed their social life and the fellowship they once had, and the depression they felt, which often stemmed from having lost their child. The women further experienced it difficult to move around because of nerve damage in conjunction, which is a well known condition described earlier (Holme, Breen & MacArthur, 2007). The women's feelings of shame, fear and isolation meant that they had not talked about their problems with others. Muleta et al. (2008) pointed out that women suffering from VVF often did not know that help was available, living as they did in areas where it was difficult to get information. The human care the women in this present study received on the ward in conjunction with the surgical treatment was important for them. The acknowledgement and fellowship they received on the ward enhanced their self-esteem. Earlier research has shown that women, who isolate themselves because of urine leakage, withdraw from the religious activities they once were engaged in (Roush, 2009). Similar experiences were shared during the group conversations. Thus the spirituality and attending to the inner self were important as natural parts of daily life in the hospital ward. The women shared a belief in God, and this was manifested in their prayers for each other and their songs of praise. They spoke of their reliance on and trust in the God they believed in, and of their conviction that He would care for them. Their faith in God also gave them hope for the future. Telfo & Roux (1998) pointed out that for people in Africa spirituality and religious conviction are important elements for dealing with their problems. A faith in God as an integral part of someone's character will be of great support at difficult times in life. It can engender a sense of trust and a meaning to life in situations where an individual has been rejected or threatened.

Finalization

This study provided new insights into understanding women's narrative experiences of living with VVF in the Librarian society. Through the women's narratives the study identified experiences of absence and reliance, something probably transferable for the understanding of women living with VVF/RVF in other social communities.

Strengths and limitations of the study

Although this present study was conducted with a small sample of women they were representative for women living with VVF. The ethnographic design afforded several advantages. It allowed a holistic perspective which aimed to understand the life situation of the women. The researcher in ethnographic fieldwork is always a participant who has to be aware of personal pre-understanding, values and beliefs. In the reflexive process the researcher had to be a reflective partner mirroring the women's experiences from an inside (emic) as well as from an outside (etic) perspective (Crang & Cook, 2007). The trustworthiness of this study is based on the long period spent together with the women on the ward, as well as on the quotes taken from their narratives. The group interaction facilitated the dialogue and allowed the women to confirm or refute the experiences of the others during the group sessions (Morgan, 1997; Burns & Grove, 2001). The authors' earlier experiences of nursing in African cultures were of importance as well as their outside perspective when going on with the analysis. There was a need to always critically review the field notes and the verbal translation of the women's narratives.

All the women who took part in the study received verbal information that participation was voluntary. However, a weakness in the study design was that the women could have felt that they were in a position of dependence. Moreover, working with interpreters was both a challenge and a resource. The Liberian nursing students assisting as translators were also participators (Crang & Cook, 2007).

Authors' contributions

All authors participated in design and plan of the study. XX made the ethnographic fieldwork and transcribed the information. All authors were involved in the analysis, the writing and finalization of the manuscript.

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