

Determinants of Duration of Leakage in Women with a Fistula Diagnosis: A Prospective Cohort Study in East African Countries.

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ABSTRACT

Introduction: Women living with Vesico Vaginal Fistula (VVF) continue to suffer for many years, and often in silence. Around the world, over 2 million women live with a fistula and new cases continue to be reported especially in low income countries. These countries also tend to have a high maternal morbidity and mortality rates.

Objectives: To establish the duration of leakage in a cohort of women diagnosed with fistula.

Methodology: A prospective cohort study conducted over a three-year period. Patients with confirmed diagnosis of VVF and or Recto Vaginal fistula (RVF) were eligible for study. A structured questionnaire was used to collect information on sociodemographic profiles, presenting symptoms and duration of leakage.

Results: A total of one thousand and twenty-four patients were enrolled in the study, 34% had lived with the fistula for more than 3 years. The majority (70%) were young, with a mean age of 20. Literacy levels were low in this cohort. Urban women were more likely to access fistula care services compared to their rural counterparts ($p > 0.0001$).

Conclusion: Individual and country level factors influenced the duration women lived with fistula before surgical repair.

Keywords: Vesico Vaginal Fistula (VVF); Recto Vaginal fistula (RVF); duration of leakage; predictors; Africa.

INTRODUCTION

In many African countries, widespread gender inequalities and weak health delivery systems contribute to delayed access to fistula care services^{1,2,10}. Fistula development is associated with the three classical delays: 1) delay in reaching the health facility 2) delays in accessing health services and 3) delays in accessing skilled birth attendance¹⁰. Although inequality in access to health care services has received focus from the perspective of health economists⁸, accurate data on obstetric fistula and issues affecting women with this condition are not readily available in Africa. In part, this is because of

variations in health status of the target population^{10,9,6}. Little is said about inequality in access to fistula care services in settings where the condition is still common.

The long-standing limitations in fistula prevention and care are a reflection of poor access to maternal health services². The failure to recognize the need for fistula prevention is largely attributed to gender bias and failure of health systems to deliver timely and efficient services when women need them most⁴. In-country health and regional infrastructure continue to complicate access to fistula care. For instance, in Ethiopia, a woman has even a greater burden

of accessing fistula care given that distance from home to the health facility range from 100 to 10km⁵. In Kenya, the average distance in accessing health services in Northern Kenya is 10km compared to 3km reported in Western part of that country⁶. To expect a pregnant woman to access skilled birth attendance when labour begins or when fistula has developed and the facility is 10 km away is unrealistic. This explains, in part, why almost half (44.8%) of Kenyan women aged < 20 years give birth at home, with assistance of a relative or a friend, despite the fact that maternal health services are free in Kenya. Home births are reported more in the rural settings than in urban settings because of various reasons including: distance to hospital, cost and lack of transport⁶. Unfortunately, it is this group of women who are also at the highest risk of developing a fistula. When the fistula develops, women can no longer keep their employment, they lose income, stress related illnesses sets in and women become disillusioned, often with suicidal tendencies¹¹. This is very common especially if they were divorced following fistula occurrence^{11,3}. Women who are divorced because of fistula tend to report self-neglect over a long period of time³.

Adequate fistula information and financial stability has been attributed to increased access to fistula services. In a Nigerian study, women are said to have travelled 1000 miles to seek fistula treatment, with an average duration of urine leakage being 61.5 months⁷. Conversely, community-based surveys in Tanzania and Uganda report the median duration of leakage being years⁵, while facility-based surveys report median period of leakage as one year⁷. These studies highlight a simple fact; that women without information on availability of fistula services live longer with urine leakage. It is not surprising that women living in the villages have an increased risk of ill health compared to urban dwellers⁸. In part, this explains the long duration of women living with fistula in Africa given that a larger population live in rural areas. The aim of this paper was to establish the association between patient characteristics and duration of leakage in seven countries; Kenya, Uganda, Southern Sudan, Somalia, DRC Congo, Malawi and Rwanda.

METHODOLOGY

Women recruited to this study attended hospital-based fistula care services in East African Fistula centres, from January 2013 to March 2017. The study was approved by Kenyatta National Hospital Ethics Review Board. Study related information was translated into Kiswahili, a local language to facilitate informed consent processes. Prior to fistula service provision, active community awareness campaigns were done to help raise awareness about the fistula problem, destigmatize obstetric fistula as well as facilitate greater access to fistula services. Upon arrival at the designated health facility, women with a history of urine and or stool leakage were informed about the availability of fistula services and preventive options. All women with a history of urine or stool leakage were screened using a standardized screening tool. The tool was developed based on WHO,2006 criterion; it looked at both history and clinical picture for the diagnosis of obstetric fistula and or recto vaginal fistula. Qualifying and consenting women were enrolled for study. A second tool was used to collect data on sociodemographic profile, fistula type and duration of leakage.

Data cleaning was done prior to data analysis. IBM SPSS Statistics, version 20, was used to analyze the data. Descriptive methods were used to estimate means, standard deviations, medians and percentages in the study sample, with 95% confidence intervals where appropriate. Data has been presented in descriptive form and tables. Duration of leakage was collected as an ordinal variable as women were not expected to be able to remember the exact number of years of leakage. Mann-Whitney U tests, independent-samples t-tests and Kendall's correlation were used to estimate the association of variables.

RESULTS

One thousand two hundred and twenty-four (1224) women with a fistula diagnosis were recruited for study over a period of three years. Duration of leakage was associated with country of referral. Kenya had the highest percentage (39.0%) of women who had leaked urine/stool for a year or less. This was closely followed by DR Congo (39.5%) and

Rwanda (14.9%). The percentage of women whose leakage had lasted more than 108 months varied from 7.9% for the DR Congo to 40.5% for Rwanda. Only three referrals from Somalia had a leakage lasting 12 months or less as shown in table 1. The distribution of duration of leakage differed significantly between centres ($p < 0.001$).

Duration of leakage by Fistula Type

The association between type of fistula and duration of leakage was not statistically significant. Fistulas were classified according to²⁰ guidelines as follows: Type 1, these were simple fistulas which did not involve the closing/continence mechanism, measuring > 5 cm from the external urethral orifice. Type II fistula were those that involved the closing/continence mechanism, measuring < 5 cm from the external urethral orifice. Type III fistulas were those that involved the closing mechanism and were more extensive, the fistula is > 5 cm from the external urethral orifice. Type III fistula were miscellaneous and involved the closing/continence mechanism. Women presented with all types of classifications: Fistula type IIBb (50.0%), combined Vesico Vaginal Fistula and Rectal Fistula (45.7%), Rectal Ib (46.7%) and Rectal and Vaginal Fistula 1c (50.0% were more likely to have duration of leakage up to 12 months:). Two classifications were more likely to be associated with durations over 108 months: RVF Ib (36.7%) and RVF IIa (31.4%). Table 2 shows associations between fistula-related details and symptoms of the women with duration of leakage. The majority, 80.6% (987), of the respondents said they had a problem with urine, 25.2% (308) said they have a problem with faeces, and 118 had both urine and faeces problems.

Haemoglobin Level: The association with haemoglobin level was statistically significant ($p = 0.007$) but this appeared to be an artefact of the large sample size because the mean levels in the four groups (12.2 to 12.6 g/dl) were not clinically different. The association with parity was significant using three different tests incorporating or ignoring order ($p = 0.002$ to 0.027).

Parity: Women with parities of 0, 2, 3 and 4 (50%, 42.4%, 46.8% and 43.2% respectively) were more likely while those with a parity of 1 (30.0%) were

less likely to have a duration of up to 12 months. Women with parities of 2 and 3 were less likely to duration of over 108 months (20.5% and 20.9%). There were no significant associations with problems with urine or faeces, while the association with passing urine normally was significant when the ordering of duration was again ignored ($p = 0.015$). Slightly more women than average had a duration of 13-60 months and slightly less than average had duration over 108 months as shown in table 2.

DISCUSSION

The prospective nature and mixed design provided a combination of both theories required to gain real understanding of the complexities of post-fistula repair. This unique approach of enquiry in this study presents new significant predictors of duration of leakage. The duration of leakage in all 1224 women was determined by four main factors; country of referral, women's characteristics, women's living arrangements, source of fistula information, childbirth-related factors and fistula-related factors such as vesico vaginal fistula or rectal vaginal fistula or a combination of both. Women referred from countries outside Kenya were more likely to have a longer duration of leakage, $p = 0.002$. Apart from Somalia where women had durations of up to 12 months, Kenya and the DR Congo had the highest percentages of women with a duration of up to 12 months. Like the rest of the countries, some Kenyan women also reported a duration over 108 months. Such observations are not unique to this study: previously, in Tanzania, studies indicate long durations of leakage³.

Women who accessed fistula care within 12 months after fistula developed reported having attended school especially up to secondary level or higher, urban dwellers and were employed with a steady income. Being single also played a role in early access to services compared to women who were married or those in stable relationships. The power to read, write and spend their income contributed to their decision in seeking fistula surgery within 12 months. These observations present new evidence where overtime, four interrelated factors; marital status, education, employment and urban dwelling consistently influenced early access to fistula

services. In addition, Women with higher education also stood a better chance in accessing fistula information via electronic or print media; compared to their counterparts who never attended school and depended on others for fistula information and reported longer duration of leakage. This observation is in agreement with previous reports which associated poverty with poor health seeking behaviour in similar cohort of women³.

Many of the factors that hinder access o fistula services are interrelated with those that hinder access to Emergency Obstetric Care: they include poverty, early marriages and early pregnancies, these issues tend to compound one another to the detriment of the young women^{7,15}.

The emerging new evidence points to situations where the presence of a relative at birth is associated with longer duration of leakage. The dynamism and interrelated factors are not well understood but the presence of a relative at birth seems to limit the woman's decision-making power when labour or fistula occurs¹⁵. Studies in other settings show that mothers-in-laws were perceived to have negatively influenced antenatal care uptake and their decisions went largely unchallenged¹⁸. Although the current study did not inquire about which relative was present at birth, in rural areas it is common to find young women living in the same homestead with inlaws and when labour begins, husbands are reported to be the primary decision makers cases where wives were younger than their husbands⁷. In the current study, women with a mean duration of labour of 46.7 hours and a mean birth weight of 3.53 kg also reported longer duration of leakage; most these women had no access to skilled birth attendance. In a previous Kenyan study, women who delivered at home said they did not find hospital birth to be necessary, a situation confirmed by other multicountry reports which show that the poorest women tend to birth at home with assistance of a Traditional Birth Attendant⁷.

The birth place seems to complicate the lives of women with fistula because the decision making process is complex involving husbands and the extended family^{7,19}. It is not surprising to find that as soon as fistula develops, partners withdraw their

emotional and economic support leaving the fistula women disillusioned, in abject poverty which predisposes them to depressive illnesses³.

Women with more than two children were likely to access care within 12 months, an indication that there are other factors that influence health seeking behaviour for these women. In this case, women may have chosen to seek fistula services early either because their self-worth was still intact or they had a desire to protect their children from societal rejection and the shame associated with urine leakage. Previously, in a sister publication, women narrated the sad events in the lives of thier children; where the stigma and name calling went beyond woman's lives¹⁵.

It was interesting to observe the role of religion in women's access to fistula care services; Muslim women were more likely to have shorter duration of compared to Christians who reported long periods; over 108 months of leakage.

Fistula type and location also determined duration of leakage. Women presenting with RVF alone lived longer and seemed to cope better with stool leakage compared with those whose who leaked urine. Those with a diagnosis of RVF alone lived with the leakage for a long period and devised coping mechanisms such as delaying meal times; fortunately, they experienced less stigma. This is understandable as negative stigma is likely to be less from an RVF than VVF since leakage of stool is easily controllable unlike urine leakage, a finding described earlier by other researchers²⁰. Those with a diagnosis of RVF alone seemed to invent coping mechanisms which helped them cope better.

CONCLUSION

Women with good education and employment had better chances in accessing surgical services within 12 months of fistula development or less. Having children influences a woman desire to access fistula care service. Urban women seek fistula care services earlier compared to their rural counterparts. Surgical closure of fistula is not enough to restore women's dignity.

Table 1: Country of Referral by Duration of Leakage

Country	Up to 12 months	13 - 60 months	61 - 108 months	Over 108 months	Total	Test results	p
	N (%)	N (%)	N (%)	N (%)	N (%)		
Kenya	354 (39.0%)	194 (21.4%)	122(13.5%)	237 (26.1%)	907 (100%)	Fisher's exact	<0.001
Malawi	5 (26.3%)	4 (21.1%)	6 (31.6%)	4 (21.1%)	19 (100%)		
DR Congo	15 (39.5%)	17 (44.7%)	3 (7.9%)	3 (7.9%)	38 (100%)		
Rwanda	11 (14.9%)	20 (27.0%)	13 (17.6%)	31 (40.5%)	74 (100%)		
Somalia	3 (100%)	0 (0%)	0 (0%)	0 (0%)	3 (100%)		
Southern Sudan	20 (28.2%)	26 (36.6%)	12 (16.9%)	13 (18.3%)	71 (100%)		
Uganda	34 (33.7%)	22 (21.8%)	15 (14.9%)	30 (29.7%)	101 (100%)		
Total	442 (36.4%)	283 (23.3%)	171 (14.1%)	317 (26.1%)	1213(100%)		

Table 2: Fistula-related details of the Women by Duration of Leakage

Characteristic		Up to 12 months	13-60 months	61-108 months	Over 108 months	Total	Test results	P
		N (%)	N (%)	N (%)	N (%)	N (%)		
Haemoglobin	mean [SD]	12.2 [1.8]	12.3 [2.0]	12.6 [1.9]	12.6 [1.9]	12.4 [1.9]	F=4.11, df=3,1208	0.007
Parity when fistula developed†	0	4 (50.0%)	2 (25.0%)	0 (0%)	2 (25.0%)	8 (100%)	χ ² trend=5.13, df=1 Kendall's τ=-0.08 χ ² =27.21, df=15	0.023 0.002 0.027
	1	158 (30.0%)	131 (24.9%)	84 (15.9%)	154 (29.2%)	527 (100%)		
	2	89 (42.4%)	46 (21.9%)	32 (15.2%)	43 (20.5%)	210 (100%)		
	3	74 (46.8%)	33 (20.9%)	18 (11.4%)	33 (20.9%)	158 (100%)		
	4	41 (43.2%)	19 (20.0%)	10 (10.5%)	25 (26.3%)	95 (100%)		
	5 or more	65 (36.7%)	45 (25.4%)	21 (11.9%)	46 (26.0%)	177 (100%)		
Problem with urine	Yes	355 (36.2%)	224 (22.9%)	133 (13.6%)	268 (27.3%)	980 (100%)	χ ² trend=1.53, df=1 χ ² =4.28, df=3	0.216 0.233
	No	87 (37.5%)	58 (25.0%)	38 (16.4%)	49 (21.1%)	232 (100%)		
Problem with faeces	Yes	103 (33.9%)	83 (27.3%)	40 (13.2%)	78 (25.7%)	304 (100%)	χ ² trend=0.01, df=1 χ ² =3.76, df=3	0.912 0.289
	No	339 (37.3%)	200 (22.0%)	131 (14.4%)	239 (26.3%)	909 (100%)		
Pass urine normally	Yes	176 (36.6%)	130 (27.0%)	70 (14.6%)	105 (21.8%)	481 (100%)	χ ² trend=3.76, df=1 χ ² =10.44, df=3	0.053 0.015
	No	266 (36.6%)	153 (20.9%)	101 (13.8%)	212 (29.0%)	732 (100%)		
Overall		442 (36.4%)	283 (23.3%)	171 (14.1%)	317 (26.1%)	1213 (100%)		

RECOMMENDATION

Further inquiry is needed to explore other fistula types of classification and factors that contribute to access to fistula care services. Also, there is urgent need for clinicians and midwives to work together in mainstreaming social reintegration, counselling and long-term follow up as integral components of a fistula care programme. This approach will ensure that post-operative complications such as: depression, loss of self-worth and loss of income have been adequately addressed, thereby facilitating full recovery of the fistula patient.

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