Individual NGO Report

to the **68th Session of CEDAW**

(Committee of the Elimination of all forms of Discrimination against Women)

2 October - 17 November 2017

(can be posted on the website)

Kenya

Issue: Fistula

the Modern-Day Leper and silent killer disease of the poor: Jamaa Mission Hospital-Kenya

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Report Tool: In-depth interview was used to obtain socio-demographic data and medical history for all consenting patients before surgery.

Findings: Women with obstetric fistula are predisposed to high levels of mental imbalance.

Recommendations: Holistic state management approach, including mental health care and family support (detailed rec. see in the report).

Attributes: Forced early marriages, rape, female genital mutilation, poverty, home deliveries, untrained midwives, long distance from health facilities, illiteracy and minimal fistula gynecologists.

Effects: Divorce, separation, chronic ailments, foul smell, paralysis, low self concept, stigma, isolation, rejection, physical abuse by partner, extra marital affairs, financial constrain, death, high child mortality.

Prologue:

The NGO has ECOSOC status since 1996.

1. This input is a submission, to bring to the UN the concerns of the most vulnerable girls and women. The organization is based in 73 countries in five continents.
   In this report we are presenting the case of women and girls who suffer obstetric fistula and live in miserable conditions.

2. **Economic, Social and Political Context:**
According to a UN-periodic report conducted between 1980-2015, on 2014 in human development index, Kenya was ranked 145, index 0.548. Kenya has the largest and most diverse economy in East Africa, with an average annual growth rate of over 5% for nearly a decade. In terms of Human Development Index Kenya ranks highest in the region. The country's population is of approximately 41.61 million people.

Kenya's political context has been heavily shaped by historical domestic tensions and conflict associated with centralization and abuse of power, high levels of corruption with the inception of devolution. Women's political representation in leadership in Kenya is below the global average, despite improvements in the recent election, triggered by the 2010 Constitution.

3. **Geographical location**, the report was conducted in Jamaa Mission Hospital managed by the Organisation where as a counsellor psychotherapist formed part of the fistula team. It is in the Eastland of Nairobi the capital city of Kenya. It was founded in 1971, as a Maternity Hospital and home for teenage mothers who were forced to se-

cure abortions or were being forced into early marriages due to pregnancy. It later developed into a general hospital.

4. Obstetric fistula is a medical condition in which a hole develops between either the rectum and vagina or between the bladder and vagina after severe or failed childbirth, when adequate medical care is not available. It is thus a childbirth injury caused by prolonged labor.

CAUSES OF FISTULA

5. Social-Cultural Practices

5.1. Forced early marriages when a girl has not matured. This practice is common among the Maasai and Meru tribes and the Muslim people in North Eastern counties in Kenya. It is a nomadic traditional practice that needs urgent action to combat. During child labor, since the body organs have not fully developed, and because of naivety, the mother has no idea about child-birth and thus cannot differentiate between normal stomach aches and labor pain. The pie chart (appendix) demonstrates teen pregnancies as 10, 12% of the total patients. Days of unrelieved labor create compression, cutting off blood supply to the baby and to the mother's internal soft tissue; those who survive must live with a never-ending flow of urine which has life-long effects.

The 1953 Convention on the Political Rights of Women, was the first international legal instrument to recognize and protect the political rights of women. The 1957 Convention on the Nationality of Married Women was the first international agreements on women's rights in marriage. These two legal documents as well as the 1962 Convention on Consent to Marriage, stipulates the Minimum Age for Marriage and Registration of Marriages.

5.2. Female genital mutilation (FGM), a cultural practice of some Kenyan ethnic groups and the Muslim community who believe that the practice reduces promiscuity among the youth. Performed by traditional medicine practitioners, it damages the vaginal organ leaving it susceptible to other ailments and injury. Due to the weakened flesh, the tear develops during child labor. FGM is prevalent among the pastoralist communities and in the North Eastern part of Kenya. See illustrated in the Chart (Appendices) which demonstrates a relative (8;10% and 8, 10%). This is evidence of the cultural and traditional beliefs, and malpractices that need to be challenged.

6. Social- Economic Factors

6.1. Unqualified paramedics, because statistics are not kept in the many hospitals and health centers, there is miss-diagnosis, in some hospitals and some injuries caused by Obstetricians. The symptoms of a vaginal fistula are very clear. A qualified

doctor will want to talk about the symptoms and about any surgery, trauma, or disease that could have caused a fistula. Unfortunately not all hospitals have fistula surgeons on their staff (See Appendix Dr. Mutiso…)

6.2. **Poverty;** it is considered a disease of poverty because of its tendency to occur in women in countries who do not have health resources comparable to developed nations. A percentage of patients come from refugee camps where there are limited medical facilities due to overcrowding, or because they cannot afford transport to the health centers. This is despite the efforts of the government through the first lady of Kenya Margaret Kenyatta who is advocating in the **'Beyond zero campaign' for** a move to reduce child mortality. In reference to a pie chart (Appendix). Nairobi has the highest number of patients treated with this (20; 25%), and this illustrates that since the patients are within the city, most do not get medical care due to poor social-economic status**.** However most the patients have migrated from the rural areas in search of treatment in the city. We commend the effort of the Government that offer free treatment services in Kenyatta Referral Hospital but due to high numbers patients queue for many months before the treatment.

6.3. **Illiteracy;** lack of knowledge of fistula and the effects increases developing the condition. Many confuse c-section as the cause of fistula. All fistula patients are taken through counseling sessions where they are psycho-educated the causes and the preventive measures. The chart demonstrates Dadaab camp in Garrisa (11; 14 %) and North Eastern with 8; 14% patients suffered fistula and were treated. Issues of concern are, limited health facilities, FGM, early marriages and minimal information on the condition among others.

7. Inaccessible **health facilities**, due to the distance many home deliveries, by untrained midwives causes more damages and increasing fistula mortality. This has been the case in Narok county with, 14 patients 18% of the total patients treated, The major reasons are minimal health centres, early and forced marriages and many other factors.

Way forward: - We acknowledge and commend the good efforts the Government of Kenya in putting in place towards implementation of Sustainable Development Goal 3 including partnership campaigns and awareness in ending fistula and child mortality.
We recommend more efforts to end fistula:-

- To urgently carry out frequent awareness-raising grass-root campaign to inform the public about the causes of fistula, contributing factors (such as Female Genital Mutilation and early marriage and childbearing), the need for facility deliveries, and the availability of treatment.
- To involve provincial administrators, religious leaders, and NGOs in the campaign.
- To seriously penalize perpetrators of FGM.
- To develop and implement a national fistula strategy in accordance with the World Health Organization's "Obstetric Fistula: Guiding Principles for Clinical Management and Program Development." Relevant government ministries, such as the Ministry of Gender and Children Affairs and the two ministries of health, and NGOs should participate in crafting the strategy.
- To work towards providing Adequate Health Services, Accountability to Prevent, Treat Obstetric Fistula.
- Where possible to expand the Community Midwifery Model to cover the whole country and address payment of community midwives.
- To implemet The Child Protection Act passed in 2007 and urgently take action against child marriages.
- To construct Health Centers close to the public in the counties where patients can easily assess treatment within the shortest time.
- To work towards putting in place more qualified fistula surgeons in all health centers to reduce the child mortality rate.

EFFECTS OF FISTULA

8. Family Dysfunctions

8.1. Domestic violence, there cases where due to the condition patients develop e.g. low libido, some end up battering the women and use of abusive language.

8.2. Divorce and separation, due to the chronic hygiene problems, accompanied by years of psychological trauma.

8.3. **Negligence, loneliness,** abandon, leaving… Many withdraw from social affairs, religious gatherings, and ceremonies due to lack of hygiene control.

Physical Conditions

9.1. Paralysis is a secondary ailment that most patients develop due to dead or non-functional nerves. Patients with this condition may not get the fistula treatment from a fistula surgeon.

9.2. High child mortality rate, obstetric fistula is one of the most serious and tragic childbirth injuries. Further, only a quarter of women who suffer a fistula in their first birth are able to have a living baby, (**Obstetric fistula - wikipedia**). It frequently occurs that these patient lose their children during labor. So after losing her baby, a woman must live with a never-ending flow of urine or stool. The acute trauma of loosing a child often remains with a woman for the rest of her life.

9.3. Sexually transmitted diseases consequences: no intimacy relationships; extra marital affairs; infected with sexually transmitted diseases HIV /AIDS; trauma; death, leaving behind orphans.

10. Psychological Conditions

10.1. Depression, women with obstetric fistula have high prevalence of depression. Greater attention therefore is needed to medical surgical and psychiatric / psychological management. Depression is significantly associated with fistula due to many years of suffering, unemployment, lack of social support; many develop suicidal tendencies.

10.2. Anxiety; the concealing of aches such as back aches leaves women with fistula in constant extreme fear and anxiety in case their relatives, in-laws or others in the community discover the truth about their conditions; what will happen: Will the in-laws send them to their biological family? Will they sideline me…?

10.3. Low self- concept; it is a psychological and emotional illness added to the physical sickness as patients often develop extreme low self esteem, negative self image. Dreams of the ideal self are shattered. These demand holistic treatment of both medical and psychological intervention. These increases high chances of feeling stigmatised wether by an internal-locus or external-locus of evaluation. Many are not able to interact for fear of being laughed at and to be isolated. Many have no dreams for the future.

10.4. Stress related disorders and mood wings; pains, insomnia, fatigue are common.

11. Scope of patients

Patients are from almost all the 47 counties of Kenya and bordering countries but mainly from North Eastern, Dadaab camp, Kakuma camp, Wajir, Marsabit, Meru, Kitui,

Narok, Kajiando, Eldoret, and the larger Rift Valley. Though Nairobi records the highest percentage (20, 25%) most of the patients are not residents of Nairobi, most are referred for treatment services from other counties. (The figure in the appendix stipulates and ascertains the demographic information of the scope of patients.)

12. Challenges in accessing patients

12.1 Mobilization: because of stigma, patients shy off from public domain which makes it even more difficult to access them. Other patients are found in distant places making it nearly impossible for them to access treatment. Criminal activity and other situations such as human trafficking, worsens the situation as some patients are discouraged to access treatment for fear of being trafficked or lost.

12.2 Mistrust: some patients don't trust male health care providers which makes it difficult for male nurses to provide them with a screening programme. This is also connected with the Some religious or cultural beliefs consider being observed this way by a man tantamount to unfaithfulness.

12.3 Prolonged suffering: because of the nature of the condition, many persons suffer in silence and as a result fail to access treatment services.

12.4 Minimal public awareness: There is minimal information of fistula condition or of the opportunities for its treatment at the hospital.

12.5 Patients are too poor to access medical attention in as much as the amenity may be close, some patients cannot afford transport to access treatment services.

12.6 Limited finances, most of the patients lack finances as they are no longer able to work. They spend money on pampers although others cannot afford even this. Some are forced to use pieces of old clothes. The condition obliges them to remain indoors as they develop wounds due to the constant urine/ stool pass.

Way forward: With the above issues I respectfully recommend that the committee asks the government of Kenya:

- To urgently improve the financial accessibility of fistula surgery by subsidizing routine repairs in provincial and district hospitals, including follow-up visits, and providing free fistula surgeries for indigent patients.

- To integrate information on fistula into the community strategy by training community health extension workers and community health workers to educate communities about fistula and to identify and refer for treatment women and girls with fistula.

Urgently improve the quality of and access to emergency obstetric care by:

- Increasing the number of health facilities in the counties that offer emergency obstetric care.

- Implementing the referral component of the Community Strategy; and completing and implementing the referral strategy.

- To penalize perpetrators of domestic violence against women.

- Assess the possibility of an exemption from user fees for all maternal health care, beyond the current exemption for childbirth in dispensaries and health centers.

- Develop and implement guidelines on the management of obstructed labor and the management of women who present with obstetric fistula immediately after birth or who present with an established fistula requiring repair.

- To put in work towards placing qualified fistula surgeons in all health centers to reduce the child mortality rate.

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Appendices:

Case study: a counseling session with Jane (given name) aged 16 years a mother of 3 children from a nomad tribe in Kenya. Jane has never gone to school, she was married at the age of 12 years lucky enough to be the only wife of a 19 year old husband.

Dr. Mutiso interviewed in Video clip attached with detailed information). (VID-20170313- WAOOOO.MP4)- Ear-phone please.

Interview guide:

1. Experience
2. Rating the performance of Jamaaa Mission Hospital and Kenyatta Referral Hospital
3. Recommendations to the government of Kenya.
4. Other remarks.

(i) **Demographic information of patients treated in Jamaa Mission Hospital in 2016**

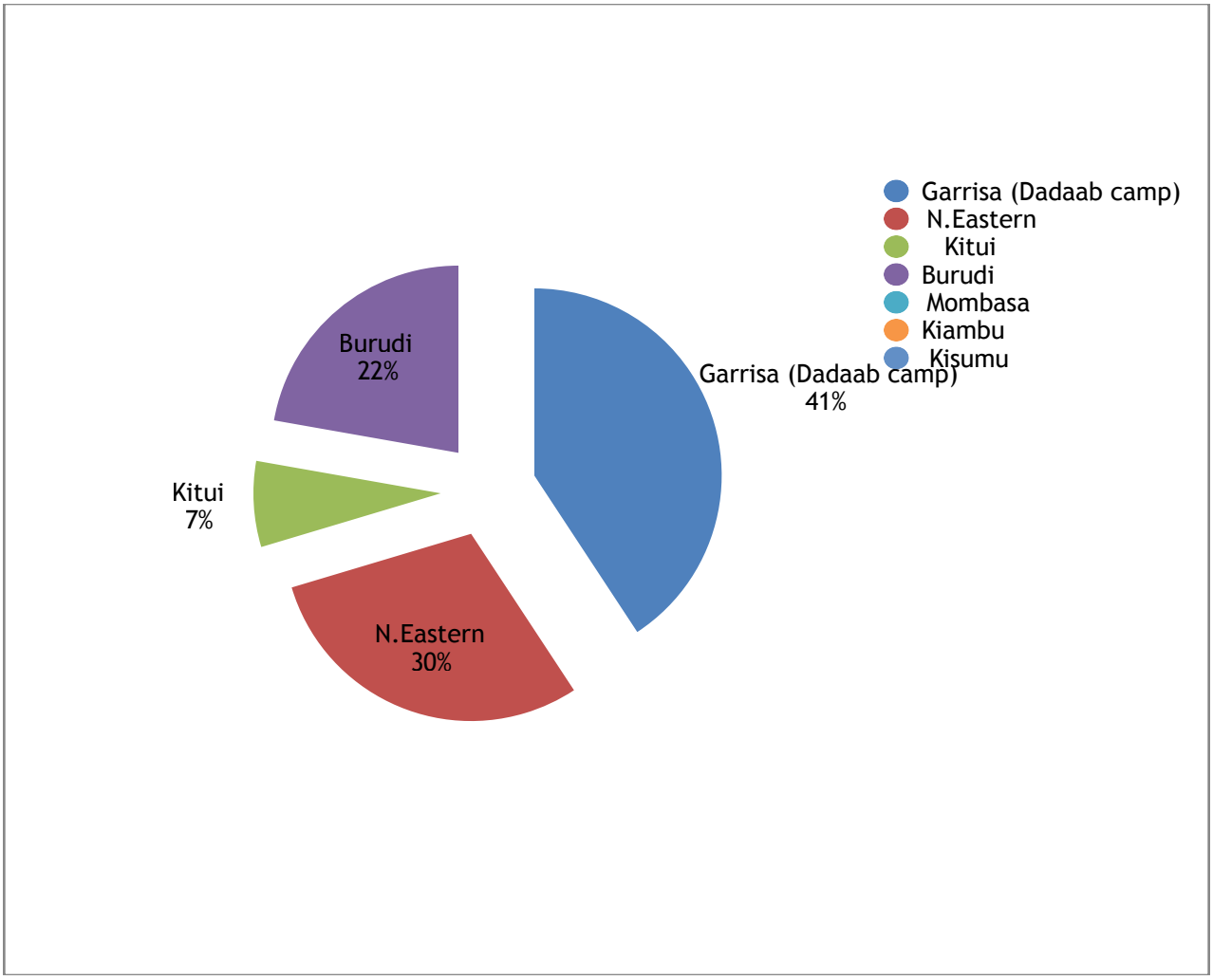
Code	Age	Residence	Home	Leakage
1	34	Kiambiu	Kisumu	Urine
2	23	Nyeri	Nyeri	Urine
3	31	Mombasa	Mombasa	Fecal
4	42	Mwingi	Kitui	Both
5	18	Hangadera	Garrisa	Urinary
6	41	Hangadera	Garrisa	Fecal
7	23	Songa	Garrisa	Urinary
8	34	Banisa	Mandera	Urinary
9	56	Songa	Garrisa	Urinary
10	19	Banisa	Mandera	Fecal
11	50	Nanyuki	Nanyuki	Urinary
12	25	Hangadera	Garrisa	Urinary
13	50	Hangadera	Garrisa	Urinary
14	39	Narok	Narok	Urinary
15	31	Narok	Narok	Urinary
16	37	Narok	Narok	Urinary
17	25	Narok	Narok	Both
18	23	Narok	Narok	Fecal
19	35	Narok	Narok	Urinary

20	21	Marsabit	Marsabit	Urinary
21	51	Tanzania	Tanzania	Urinary
22	40	Talek	Eldoret	Urinary
23	22	Ntulele	Narok	Urinary
24	32	Masai mara	Narok	Fecal
25	29	Kamikunji	Nairobi	Urinary
26	26	Kangemi	Muranga	Urinary
27	24	Kapnanda	Nakuru	Urinary
28	32	Banisa	Moyale	Both
29	34	Tinet	Nakuru	Urinary
30	32	Embakasi	Nairobi	Fecal
31	32	Chebarsiat	Baringo	Fecal
32	34	Embakasi	Nairobi	Fecal
33	47	Kakuma	Turkana	Fecal
34	26	Murot	Narok	Urinary
35	32	Ololunga	Narok	Fecal
36	16	Narosura	Narok	Urinary
37	18	Narok	Narok	Fecal
38	29	Embakasi	Nairobi	Urinary
39	42	Embakasi	Nairobi	Urinary
40	29	Embakasi	Nairobi	Fecal
41	63	Rongai	Nairobi	Urinary
42	21	Kayole	Nairobi	Fecal
43	39	Utawala	Nairobi	Urinary
44	37	Kayole	Nairobi	Fecal
45	18	Kathanga	Tharaka	Urinary
46	45	Kakauni	Tharaka	Urinary
47	30	Sirwa	Baringo	Fecal
48	43	Kariombangi	Nairobi	Urinary
49	37	Tigania	Meru	Urinary
50	32	Pipeline	Nairobi	Urinary

51	30	Moyale	Moyale	Urinary
52	42	Mioyo	Meru	Fecal
53	19	Marti	Saburu	Urinary
54	40	Mathare	Nairobi	Urinary
55	16	Kakuma	Turkana	Fecal
56	38	Komarock	Nairobi	Urinary
57	21	Narosura	Nar0k	Urinary
58	23	Nguba	Nairobi	Fecal
59	33	Kakuma	Turkan	Urinary
60	25	Narok	Narok	Fecal
61	57	Ololulunga	Narok	Urinary
62	26	Dadaab	Garris	Urinary
63	18	Dadaab	Garrisa	Urinary
64	30	Tigania	Meru	Urinary
65	30	Meru	Meru	Urinary
66	32	Pangani	Nairobi	Fecal
67	30	Umoja	Nairobi	Fecal
68	23	Marsabit	Marsabit	Urinary
69	42	Barut	Nakuru	Fecal
70	19	Kikombe	Kitui	Fecal
71	31	Maua	Meru	Urinary
72	26	Wajir	Wajir	Fecal
73	29	Ruiru	Kiambu	Urinary
74	35	Utawala	Nairobi	Fecal
75	36	Mathare	Nairobi	Urinary
76	31	Tharaka	Meru	Urinary
77	27	Umoja	Nairobi	Fecal
78	26	Mwiki	Kiambu	Fecal
79	24	Buwa	Wajir	Fecal
80	32	Karatina	Nyeri	Fecal

NB/ The total number of patients treated was 80, while there were referred cases to Kenyatta Hospital as some patients were presented with other ailments that could not be catered for by the Hospital.

(ii) Residence pie chart of fistula patients

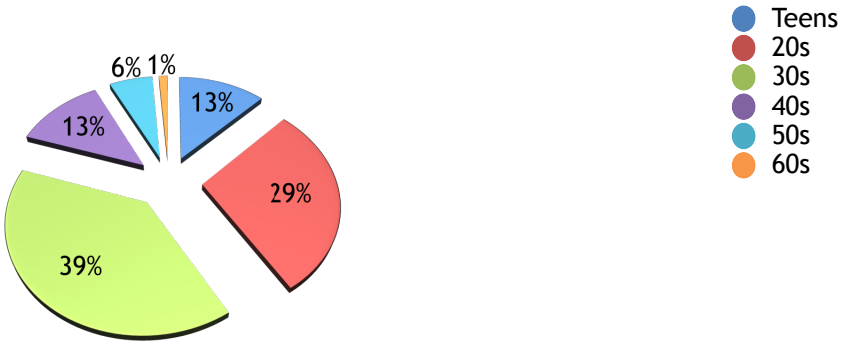


According to the above pie chart, majority of the patients are found in Nairobi with 25% of the total patients treated. This is because the patients are in search for medical treatment in the city, however, most of these reside in the rural set-ups.

The nomadic communities have a higher percentage of women and girls due to forced early marriages, FGM and long distances to the medical centers, at the same time the social economic development affect the situation. The percentages are Narok, 18%, Meru 10% and north eastern at 10%.

The refugees form another high component mainly coming from neighboring war-torn countries; these are Dadaab camp in Garrisa with 14% and Kakuma Camp in Turkana with 3%, a total of 17%.

(iii) Pie chart with Age for patients



Most of the women affected are in the child bearing age within the range of 30-39 years scoring 39% followed by 20-29 years with 29%. However, most of the patients have lived with the condition for a long time because of lack of information and medical facilities.
The early and forced marriage is of major concern as to the teenage with 10% that need to be factored in the recommendations.

Jamaa Mission Hospital.

The Organisation reaches out to the suffering and the forgotten by the government and the society. Patients with complicated and other ailments are referred for treatment from Kenyatta referral Hospital in the city where patients are treated at no cost. This referral Hospital is sponsored by freedom from fistula foundation and partly the government of Kenya. Even though patients flood in for treatment, waiting for treatment can take more than a year.
