Preventing & Destigmatising Obstetric Fistulas in Kenya

ACKNOWLEDGEMENTS

This research was supported supported by Médecins du Monde (MdM). We would like to thank our colleagues Toby McMaster and Siobhan Botwright for providing constant support, assistance with editing and comments that greatly improved the manuscript. We are grateful to the whole Polygeia team for organising the conference and providing a platform that allowed us to present our paper and conclusions.

All of us on the Women's Health team would also like to thank Adwoa Kwateng-Kluvitse from FORWARDUK, who presented FORWARD's work on obstetric fistula at the conference and provided insight and expertise that greatly assisted the research.

We would also like to show our gratitude to Elizabeth Rafii-Tabar for dedicating much of her time to putting us in contact with various experts and researchers within Women's Health.

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ACRONYMS

BC	Birth Champion
MDG	Millennium Development Goals
MdM	Médecins du Monde
NGO	Non-Governmental Organisation
NTD	Neglected Tropical Disease
RVF	Recto-vaginal Fistula
STI	Sexually Transmitted Infection
TCC	Tertiary Care Centre
TBA	Traditional Birth Attendant
VVF	Vesico-vaginal Fistula
WAHA	Women and Health Association

DEFINITIONS IN WOMEN'S HEALTH

Obstetric relates to childbirth and the processes associated with it (see **Figure 1**)

Fistula is the abnormal passageway between two organs in the body or between as organ and the exterior of the body

Intrapartum Period **is** the time from the onset of labour to the end of the third stage of labour.

Primipara is a woman giving birth for the first time

Stigma is a mark of disgrace associated with a particular circumstance, quality or person

Surgical Condition is a medical condition treated by surgery, such as a fistula. They can affect the quality of life and ability of the sufferer to work. They make up 11% of the global disease burden, which can be compared to NTDs, which made up only 1.3% in 2006 (15)

Tradition Birth Attendant is a person who assists the mother during childbirth and who initially acquired her skills by delivering babies herself or by working with their TBAs. There are government initiatives to train them as they deliver up to 75% of babies in Kenya.

SUMMARY OF POLICY RECOMMENDATIONS

COLLABORATION OF FOREIGN AGENCIES AND GOVERNMENT

1 Engage with international agencies or NGOs to provide initial funding, planning and resources

2 Nominate a central 'Fistula Co-ordinator' within the Ministry of Health to oversee the integration of the government and agency/NGO activity

TRAINING AND EDUCATION OF MORE BIRTH ATTENDANTS

3 Retrain TBAs to enable them to become effective and valuable clinical assets in order to make best use of an existing resource often well trusted within the community

4 Transport surgeons to inaccessible rural and urban areas using the mobile clinic to train new birth attendants and carry out surgeries

5 When there is a scarcity in funding, carry out an intensive 5-day training course for birth attendants

6 When more funding is available, invest in updating the curriculum for nurses and improve their salary and benefits to encourage others to join

7 Run a 3-year training programme to produce Birth Champions

RAISING AWARENESS

8 Use posters, SMS and radio announcements as an inexpensive and efficient way to raise awareness for both the community and the sufferers

9 Run discussions in public spaces to reduce stigma

REHABILITATION

10 Provide collaborative counselling for both the sufferers and their families and friends to improve self-esteem

11 Empower women returning to their community by providing them with vocational skills such as animal husbandry, literacy, sewing, soap-making and arithmetic

12 Make microcredit loans at low/zero interest available to patients to ensure they have resources to start using their skills

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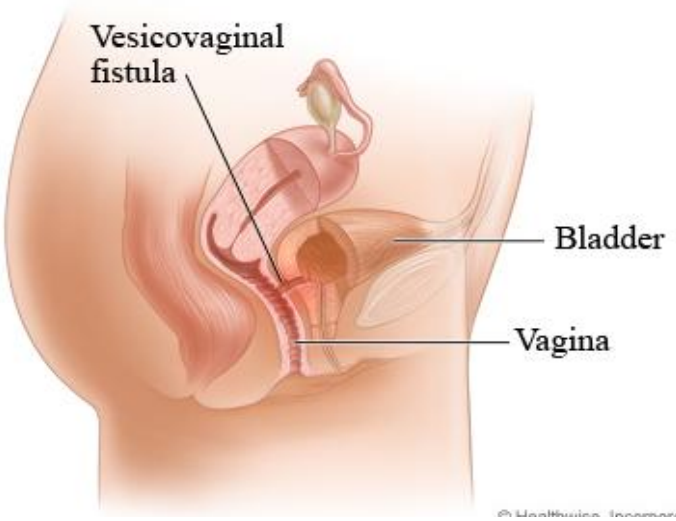

Figure 1 Diagram showing where an obstetric fistula, a vesicovaginal fistula in particular, may occur

Obstetric fistula is a surgical condition where a fistula (passageway) develops after prolonged, obstructed labour (1). A fistula may develop between the rectum and the vagina (rectovaginal fistula, RVF) or between the bladder and vagina (vesicovaginal fistula, VVF). Obstructed labour is caused when the foetus cannot fit through the birth canal. This occurs either because the pelvis is too small, the foetus is too large or abnormally positioned, or there is damage to the vaginal canal (often caused by sexual assault). Once labour starts, the uterus contracts until the contents have been expelled, the uterus ruptures or the mother dies (1). During labour, the obstruction, often the foetus' head, wedges itself deeper into the pelvis until it reaches the pelvic bone, as shown in **Figure 2**. The uterus continues to contract trapping the tissues and eventually shutting off blood supply. The tissue of the foetus then starts to soften and waste away, creating a fistula between the urinary tract, or rectum, and the vagina. From this tract, urine or stool may continuously leak (see **Figure 3**). An untreated obstructed labour may last for a week of agonising pain, then leave the mother incontinent (2). In such protracted labour, foetal mortality exceeds 90% (2). The entrapped foetus dies from asphyxiation and its tissue decays within the birth canal. At this point, either a stillbirth occurs, the uterus ruptures due to continuous contractions, or the mother dies from haemorrhaging, infection, exhaustion, dehydration, or a combination of all.

As Wall (2012) states, the pain suffered from obstetric fistula 'is almost unimaginable to those living in resource rich countries" (1), and it only begins with labour. The women who survive often return to their communities and suffer from strong stigmatisation; this is because many do not understand that it is the result of obstructed labour and instead consider it retribution for immoral behaviour. Many women are divorced by their husbands and cast out of their community (3) where they may continue to suffer from pelvic pain, vulvar dermatitis, incontinence and lumbo-sacral nerve damage, as well as mental health issues such as depression and post-traumatic stress disorder (3).

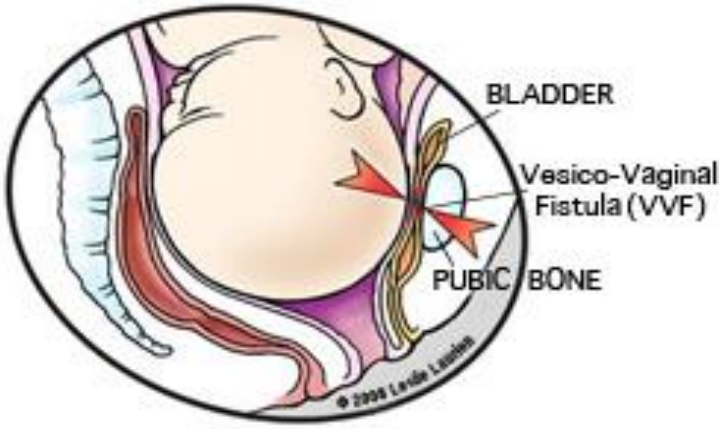

Figure 2 Diagram showing pressure from a foetus' head, leading to fistula formation

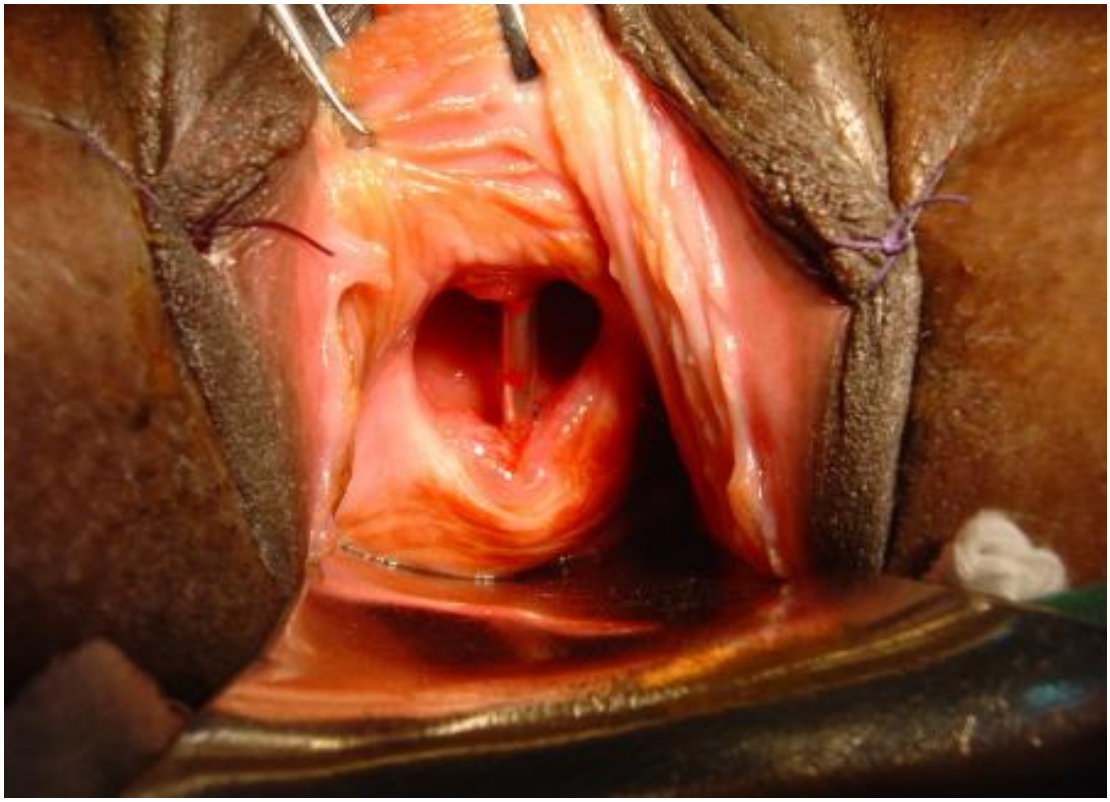

Figure 3 Transvaginal view of a fistula. Pressure from the entrapped foetal head has interrupted blood supply resulting in tissue necrosis and a fistula. A metal catheter is placed in the defected bladder base

1.2 The Global Distribution of Obstetric Fistula

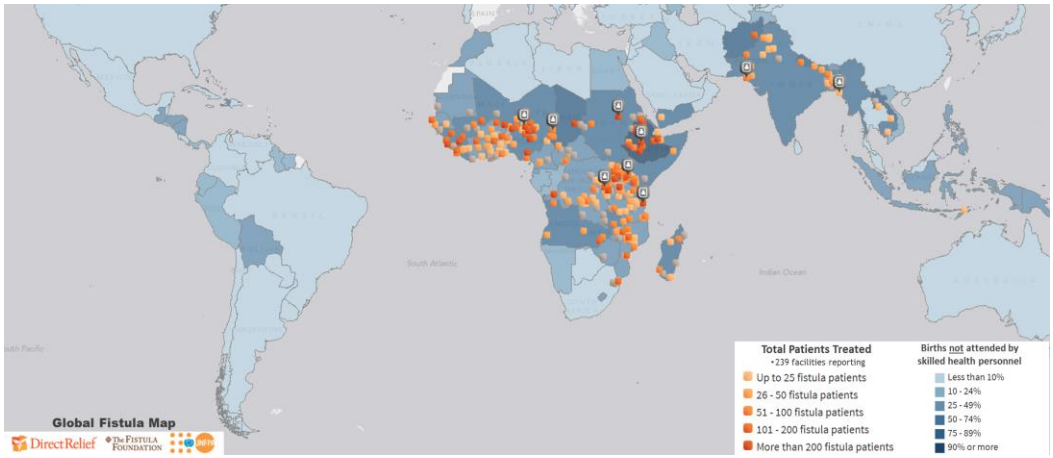

Figure 4 Map showing global distribution of obstetric fistula. Practically eradicated in Western countries, hot spots include countries like Kenya, Ethiopia, Uganda, Niger, Nigeria, Afghanistan, Sierra Leone and Nepal

Obstetric fistulas are preventable; if obstructed labour is diagnosed early on and the appropriate surgery is implemented, then survival of the mother and foetus is highly likely (4). However, this requires a skilled birth attendant to make the correct diagnosis and perform the procedure. The improvement of modern healthcare and obstetrics in Europe and North America means obstetric fistulas have not been prevalent in Western countries for over 150 years (1). Yet 3.5 million women in resource-poor countries are still afflicted with the condition and up to 130,000 new cases occur each year in countries like Kenya, Ethiopia, Uganda, Niger, Nigeria, Afghanistan, Nepal and Sierra Leone (4). This policy paper addresses obstetric fistulas in Kenya, where there are around 3,000 new fistula cases each year, while the backlog of those living with fistula is estimated to be between 30,000 and 300,000 cases (5). Estimates for prevalence are often quite rough as many cases go unreported; it is believed only 7.5% of the new cases in Kenya are reported and treated (5).

Kenyan Fact File	
Population:	45,010,000
Average birth per woman:	3.54
Physicians per 10,000 people:	1.8/10,000
Birth attended by skilled personnel:	43.8%
Chances a woman will die during childbirth:	1 in 53
Female life expectancy:	65.01 years
Population living in rural areas:	75.6%
Population living under $1.25/day	43.4%

This paper aims to use integration, destigmatisation and rehabilitation, not just to reduce prevalence of obstetric fistulas but also empower and improve the status of women currently suffering in Kenya. This should provide a long-term and self-perpetuating solution that, in the end, doesn't require intervention from international agencies. The first step involves creating a solid foundation of clinics and educated midwives, surgeons and birth attendants, all of which require resources, time and funding. Foreign agencies, such as Hamlins in Ethiopia, can provide the initial resources, education and financial backing. Therefore, initial integration between Non-Governmental Organisations (NGOs) and the Kenyan Government is required, as will first be discussed. The paper will then address the importance of providing obstetric courses and training new birth attendants, surgeons and midwives, looking particularly at the successful case study of Fistula Fortnight in Nigeria. Nepal will then be used as a comparative study to highlight the importance of community collaboration with policy-makers, and reliable infrastructure for healthcare. The role of education in destigmatising obstetric fistulas will be addressed, focussing on simple, on-the-ground techniques such as radio communication to raise awareness. Finally policies for rehabilitation through counselling, community engagement, microcredit and vocational skill development will be suggested.

2. INTEGRATION

2.1 Role of NGOs and Government

Like many neglected conditions the number of people suffering from obstetric fistula has increased untreated and incidence remains high. Reducing incidence in affected countries requires a multifaceted approach, which involves addressing the complex causal factors and reducing prevalence by treating current sufferers. This is a considerable task that no one organisation can approach alone. The health ministries of the governments are key in facilitating long-term solutions, but they require the expertise of NGOs and charities that can co-ordinate changes across regions and nations. Such collaboration is required to treat the devastating caseload in Kenya.

The importance of intervention

Neglected Tropical Diseases (NTDs) are less prevalent than surgical conditions perhaps due to the relative ease and low cost of treating infectious conditions, as compared to the task of treating surgical conditions, illustrated in **table 1**. Further to this, surgical conditions were not comprehensively addressed in the Millennium development goals (MDGs) set by the UN (6), save for emergency obstetric care outlined in MDG5.

Table 1 Cost-effectiveness of disease intervention in Disability Adjusted Life Years (DALYs) (2). This demonstrates that basic surgery provision is around 20 times more cost-effective than standard HIV-therapy

Intervention	Cost-Effectiveness
Rapid impact packages for NTDs	US $2-$9/DALY averted
Measles vaccination	US $5/DALY averted
Basic surgical services	US $11-$33/DALY averted
Antiretroviral therapy for HIV	US $300-$500/DALY averted

Current approaches

Action on the fistula problem varies in prevalence and scale across afflicted countries. In countries such as Ethiopia, there are estimated to be between 36,000 and 39,000 women living with fistula, and over 3,000 additional new cases each year (7) An Australian couple named the Hamlins have set up a number of hospitals providing access to fistula treatment.

Activity is not limited to reparative surgery; preventative measures vary in effectiveness across the developing world. The Hamlin foundation is once again a good example. Their training programme for midwives allows more births to be attended by those capable of spotting the warning signs of obstructed labour, so that appropriate hospital referrals can be made early on. Despite prevention strategies being available, current NGO intervention is often more focused on reparation rather than the implementation of widespread preventative measures. Interventions such as the education of young girls, provision of better obstetric care and destigmatisation of the condition in communities lie within in the governments' domain. The effectiveness of government contribution will be further discussed later.

Collaboration is increasingly common: for example, the Campaign to End Fistula includes organisations such as African Medical Research and Education Foundation (AMREF), Fistula Foundation, The International Federation of Gynaecology and Obstetrics (FIGO) and the United Nations Population Fund (UNFPA). Widespread participation doesn't lead to widespread care however, with localisation of services leading to a 'geographical lottery' for afflicted women, many of whom undertake long, expensive journeys across states and borders to find treatment.

2.2 Recommendations

Currently, the situation regarding obstetric fistulas leaves a lot to be desired. However, the role of NGOs and charities should not be underestimated and may reduce incidence by following the steps outlined in the flow chart below:

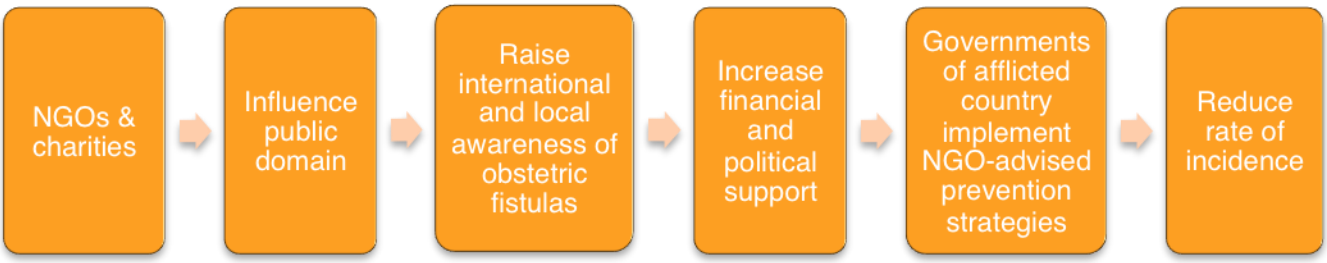

Figure 5 Flow chart showing the actions that could be taken to optimise the effect of NGO in reducing obstetric fistulas

A review of the literature marks three clear main approaches that need to be taken. These strategies are very similar to current approaches involving NTDs (1). This has the advantage of using a pre-existing framework from which to function. Listed below are the three suggested approaches:

Adaptation Approach	'Means to Treat' Approach	NGO-Public Partnership Approach
• Fistula should be viewed more like an NTD to receive more funding and awareness	• Training and retaining surgeons/mid-wives capable of fistula repair (5)	• Encourage the manufacture of basic surgical supplies
• Fundrasing and advocacy methods like those used for NTDs would supply the necessary human and physical resources (2)	• E.g. UNFPA two-week intensive assessment and referral course, which recommends the training of a core doctor/nurse team to carry out further internal training at their health facility (3), creating a 'fistula champion team'	• Supplying generic resources would reduce costs of importing goods (4)
• Adaptation is still necessary due to the complex surgical conditions of obstetric fistulas	• May lead to widespread dissemination of basic fistula knowledge	• Provision of basic surgical services is a cost-effective way to improve the state of health of a country and would allow numerous conditions other than obstetric fistula to also receive attention
• E.g. Not-for-profit drug companies produce treatments for NTDs	• Time and cost efficient	

Figure 6 Showing three different possible approaches NGOs could adopt that work within pre-existing frameworks

2.3 Fistula Fortnight

Figure 7 UNFPA Fistula fortnight treatment site states. Post-operative care: Nigeria

Fistula fortnight was an intensive two-week, NGO-government collaboration to reduce the backlog of obstetric fistula in Northern Nigeria (see **figure 7**) in 2005 (8). Nigeria, along with Ethiopia, is considered a continent-wide leader in fistula repair and is more active in fistula reduction than many other African countries. The success of Fistula Fortnight (see **figure 8**) makes it an example of co-operation between NGOs, charities and government organisations working in collaboration to produce an effective intervention (9). Kenya has a large backlog of women with obstetric fistulas and could benefit from a programme such as this. However, as indicated in **figure 8** there are certain structural limitations in Kenya that would make the implementation difficult. Overall, Kenya would need to improve its basic facilities across the country to receive maximum benefit from such a high-cost, high-commitment time-consuming event.

Prevalence in Nigeria	• 400,000-800,000 living with fistula (9) • 20,000 new cases per year
Treatment in Nigeria (2004)	• 52 resident fistula surgeons present (8) • 4,140 women treated annually - Kenya treated 225/year at the same time (8)
Fistula Fortnight Benefits	• 569 women treated during the Fortnight (8) • 87.8% successful closure rating (8) • Organised media coverage, e.g. radio channels, increased international and local awareness of fistula
Problems with Fistula Fortnight	• Collaboration events require high levels of co-ordination and commitments • It is difficult to implement in areas without pre-existing infrastructures like fistula hospitals and surgeons • It was only a short-term solution in Nigeria and didn't leave a legacy where fistula incidence would reduce for the long term

Figure 8 Showing the prevalence and treatment of obstetric fistulas in Nigeria. Highlights the success of Fistula Fortnight and why it may be difficult to implement in Kenya

2.4 Role of the Government and foreign aid

A 2014 WHO report stated that 'Women with obstetric fistula are indicators of the failure of health systems to deliver accessible, timely and appropriate intrapartum care' (10). Government-NGO partnerships can be incredibly effective, but the NGO should model its policies within the restrictions of the country involved. For example, training Traditional Birth Attendants (TBAs) have been previously proposed as a means to implement better obstetric care in rural communities with varying degrees of success (11); however, TBAs are currently outlawed in Kenya, despite attending an estimated 70-80% of deliveries in surveyed districts (12).

Responsibilities of the government

Basic maternal care may be free in Kenya; however, transport and living costs at hospitals prohibit most women from receiving obstetric care. Ultimately, the Kenyan government has a responsibility to its citizens to provide the infrastructure not only for obstetric fistula treatment and prevention, but to also ensure that interventions are long lasting. The following bullet-points list the key changes the government in Kenya should implement:

13 Education of young women
14 Increased provision of trained midwives
15 Increased availability of facilities capable of performing emergency C-sections
16 Localisation number of local clinics to reduce transport costs and delays in reaching care

Education plays a key role in prevention, it supplies more midwives for the public and increases awareness of obstructed labour and its resulting morbidities. In Burkina Faso, a study found that 86.4% of those young girls aware of obstetric fistulas knew via word of mouth or media, with only 13.6% knowing of the condition from school lessons (13). Only 50% of those surveyed had had any education, highlighting the effect that education can also have on the health of a population. An integrated programme could have the potential to address a number of conditions by advising contraception in the prevention of obstetric fistulas in the young, and infections such as HIV/AIDS and STIs.

Despite some fistulas resulting from poorly performed C-sections, this is rare enough that education of general surgeons carrying out this procedure will likely not have a significant impact on fistula incidence. A study carried out in Iran found that education of such professionals didn't lead to significant change of incidence, as fistulas mainly occur when facilities are not accessible rather than as a result of inadequate care (14,15).

Specific training can, however, decrease prevalence as surgeons are trained to close the fault. A redevelopment of basic obstetrics/gynaecology training courses for young surgeons to include fistula assessment and surgery would make the required skills more widespread while reducing the stigma faced by women seeking treatment in general hospitals Having a number of repair centres across the country would increase awareness and the knowledge that fistula is a treatable condition. An alternative would be to situate a handful of well-trained closure surgeons in specific fistula hospitals, although this introduces the same transport and accessibility problems as those faced by women seeking complex obstetric care at present.

The best way of combining prevention and treatment strategies is via the government, but foreign expertise and encouragement are needed. Adapting an NTD-like approach to make the strategies relevant to surgical conditions shows the most promise, as the strategies are known to be successful in existing cases.

The role of foreign agencies

Foreign agencies such as NGOs often work locally, but working with government agencies could ensure more comprehensive, scalable interventions. Fistula Fortnight is a prime example of such a provision. Advising the government over the long term could also maximize the impact that an NGO can have in a country. In a UNFPA report four rural areas were surveyed, revealing that no key obstetric staff there had had any fistula repair training (12). Any expert surgeons tend to be concentrated in Nairobi, a central city difficult to reach for many women due to financial and geographical reasons. Having regional fistula centres would provide care where it is needed most. It has been successful in the region of Mopti, Mali, where a Médicins du monde funded fistula centre in a regional hospital allowed the successful closure of 84.3% of 1,054 obstetric fistula cases over approximately 17 years (11), simultaneously training young local surgeons to continue the work once MdM left the area.

Co-ordination responsibilities

Foreign agencies could maximize their impact in a country by collaboration; this ensures that efforts are not simultaneously neglected in one region but increased in another. Further to this, a combination of NGO strategy expertise and the government's knowledge of the country could lead to innovative, widespread intervention. The foreign NGO, like MdM, can help with funding and planning of local clinics, as well as provide the training of mid-wives and surgeons. These are the parts of the puzzle that governments often struggle to coordinate. Therefore, a central 'fistula co-ordinator' could be nominated in the ministry of health to enable such collaborations. This has the added benefit of avoiding the problems of data collection duplications (12); giving more reliable data estimates of the national fistula burden than those currently available (10).

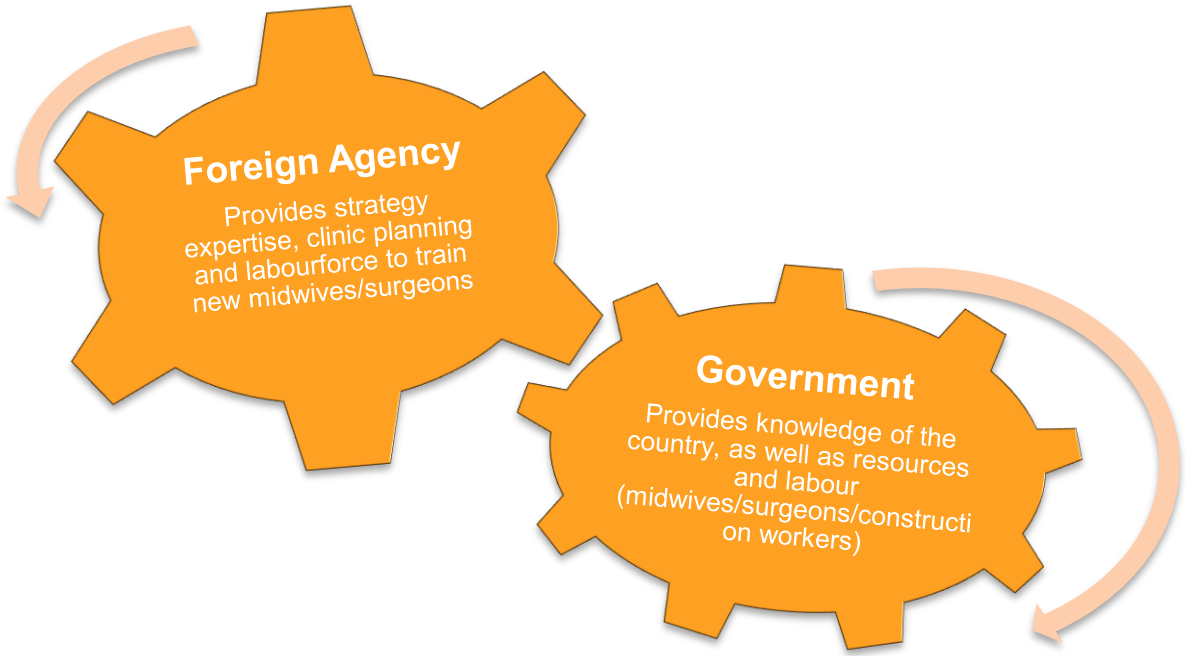

Figure 9 Illustrating the different actions foreign agencies and the Government should take to integrate properly and efficiently

3. COMPARATIVE STUDIES

In 2011, the UNFPA identified poor integration of services as a factor that affected the delivery and consistency of maternity services in Africa, the Middle East, India and Nepal (16). An additional hurdle in fistula treatment is whether people choose to initially seek health care treatment. It is necessary to find a way to integrate traditional maternity and labour beliefs, and the health care system. This paper will use Nepal as a comparative example to Kenya for fistula treatment. It is important to acknowledge that there are cultural, geographic and religious differences between these two countries. However, they both share a high incidence rate of fistula and are in the early growth stage of economic development. They therefore may both be used as sources of comparison for treatment in obstetric fistula.

3.1 Nepal

An analysis of 23 previous patients with Vesico Vaginal Fistula (VVF) over a 3-year period found obstructed labour was most commonly responsible for causing VVF (17). Seven of the nine primiparas lost their babies during birth, demonstrating the inadequacy of maternity services. Four of the patients developed VVF after destructive surgery performed in a district hospital. These patients were subsequently referred to the Tertiary Care Centre (TCC – a highly specialised medical unit), where 56.5% of fistulas were successfully repaired. This example highlights the discrepancies in treatment quality at different levels of health care. TCCs were better at educating their patients on the risks leading to fistula (17). However, they are not widely available treatment options; district hospitals are more accessible. Patients often only reach TCCs after a major problem such as obstructed labour and rupture has occurred.

Prevention is better than cure, so a framework in which quick referrals to well-equipped centres in times of obstetric difficulty is needed. This framework needs to have similar levels of communication and management as the transition between GP, midwifery services and hospitals in the NHS. In particular, there is a focus on the coordination of different agencies within the health service and the attempt at standardised care. These are similar principles to those the NHS is structured around. Therefore, standardisation of care is crucial to reducing prevalence and incidence of obstetric fistula.

3.2 Kenya

The public health system accounts for 51% of the health care available in Kenya. Private, NGO and faith-based organisations account for the remaining 49% (19). Similar to the discrepancies in treatment in Nepalese hospitals, a lack of centralized infrastructure within the healthcare system led to increases in infant and child mortality (19). Health Sector Strategic plans were introduced to try to combat this issue. Key stakeholders such as development partners, NGOs, and teaching and research institutes were invited to join the Ministry of Health's planning process. An independent evaluation in 2004 found that the implementation of the first National Health Sector Strategic Plan (NHSSP) did not manage to make a break through transforming critical areas of the health sector. Significant problems were similar to those faced in Nepal: an absence of legislative framework and a lack of institutional coordination. These problems have a dramatic impact on the availability and consistency of maternity services and the treatment of obstetric fistulas.

Integrating cultural beliefs

Integration can be narrowly viewed as coordinating and managing health services. In order to have a long lasting and effective impact, it is crucial to integrate cultural beliefs into the health care system. Three phases of delay have been identified in health care (20):

- Delays deciding to seek care
- Arriving at the hospital
- Access treatment after arrival

Cultural beliefs combined with a lack of female empowerment, economic constraints and inaccessible hospitals are all factors that contribute to delays in women experiencing obstructed labour seeking hospital care in resource-poor countries (20). Therapeutic pluralism involves multiple different healing pathways, for example placating supernatural forces thought responsible for delays in delivery (20). As a form of traditional medicine, it is often the preferred treatment method, delaying the decision to seek medical attention. The prevention of Maternal Mortality Network found that the modern-health care system is used only as a last resort. In order to overcome this initial delay in choosing to seek care in cases of obstructed labour, cultural beliefs need to be integrated into the care structure to reduce incidence of obstetric fistulas. This may involve the integration of TBAs, as will be discussed in **Section 4.2.**

3.3 Recommendations

Summary

- Integration between local communities and the government, to create policies that work on the ground.
- Collaboration between partners in maternal healthcare and NGOs involved with fistula care.
- Raising awareness on obstetric fistula through posters and radio channels.
- Train local midwives and surgeons in obstetric care.

Health care system integration

Overcoming poor integration of services will help to create a more coordinated and comprehensive service to prevent and treat obstetric fistulas. There are several central recommendations to policy makers. Grass-roots target setting has previously been implemented in Kenya, trying to ensure that local communities input is incorporated into health policy. It was found ineffective as community views were ignored at policy level (21), however independent reviews and evaluations could help to monitor this initiative.

Additionally, there is a need for a greater involvement of key partners in maternal healthcare and obstetric fistula NGOs, such as Gynocare Fistula Centre (Kenya), in planning, budgeting and monitoring health sector actions. The specialist and focussed knowledge of these organisations will help strengthen the health care systems approach to maternity care and fistula prevention.

Radio Communication

Making information regarding obstructed labour treatment options and risks more widely available is a priority. FM Radios in Kenya have proved a useful tool for facilitating dissemination of health care information and health care education (21). Radio communication is an effective and easy way of promoting maternal health care and integrating local and district services in low resource areas. Advantages of radio communication include:

- Inexpensive
- Integration between centralized healthcare broadcasting authority and maternal healthcare services.
- Not reliant on electricity- solar powered
- Broadcast over a large geographic area
- Broadcasts can be in several languages, such as French and Swahili.

Figure 10 Example of a campaign poster used in Niger

Posters

Even the simple act of putting up posters within local communities can help reduce stigma. Posters may help the women feel less ostracised from society as it shows other women are suffering. It also provides them with information of where to go and who to call to seek help. This is a simple and cost-effective method on spreading awareness and reducing stigmatisation.

Integrating culture and healthcare

Intensive community education about obstructed labour will help to combine underlying assumptions about the nature of giving birth with medical advice. Prenatal care must be efficient and wide reaching to inform as many communities as possible about treatment options and the importance of seeking help in situations of obstructed labour. Treatment in such situations is possible through the delivery of competent and accessible emergency obstetric services. Skilled midwifery care should increase in availability at local levels (20), integrating the national maternity care framework and local ones.

Mobile Clinic

The mobile clinic is an efficient and relatively cost-effective method of transporting surgeons and birth attendants to inaccessible areas. Although there is a high-start up cost, it is much lower than constructing a clinic and has added benefits of increased flexibility and accessibility to areas clinics could not reach. MdM uses the Mobile Clinic, see **figure 11**, all over the world, from delivering sterile needles to drug addicts in Montreal, Canada, to providing hepatitis A vaccinations in Dar es Salaam, Tanzania. In 2014, the mobile clinic made it possible to offer 3000 medical consultations, give 180 hepatitis A and B vaccinations, and administer 1500 screening tests for HIV (22). **Figure 12** provides the different possible uses of a mobile clinic when addressing obstetric fistulas in a community.

Figure 11 Mobile Clinic used by Médecins du Monde.

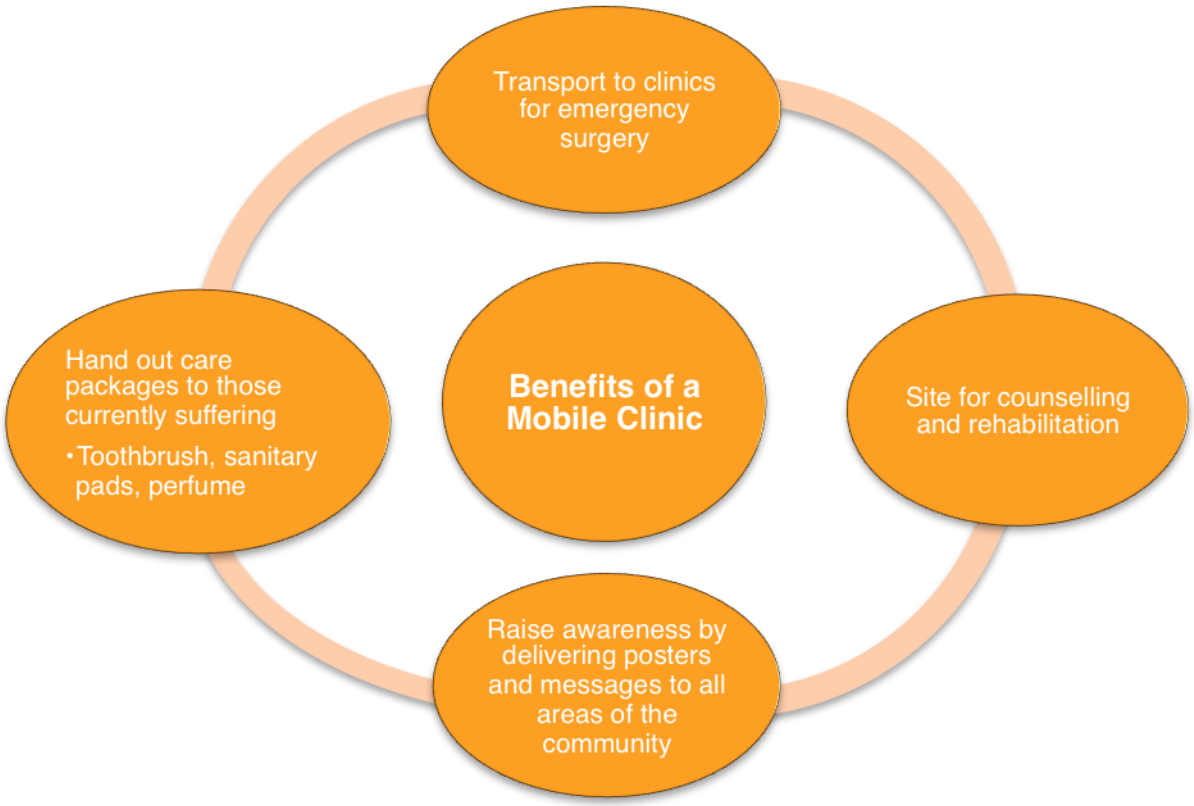

Figure 12 Illustrating the five main uses and benefits of a mobile clinic

4. DESTIGMATISATION

4.1 What is Stigmatisation and why does it occur?

For women living with obstetric fistula, the extreme stigmatisation they suffer in their communities only compounds the misery of their condition, see **figure 13**. Stigma stems from ignorance about the causes of and problems associated with fistula. This is exacerbated by the initial poor socioeconomic status of the women in question. Those affected are often very young, uneducated brides from poor or rural communities (23). These facts are further complicated by the highly patriarchal nature of traditional Kenya, where a woman's worth is inextricably linked to the strength and number of her children. Particularly in agrarian and semi-nomadic areas, children are a measure of a family's wealth, as both a source of labour and a future economic asset (24).

In many communities, Fistula is regarded as a punishment for female lust and promiscuity (24). This is not unique to Kenyan society; throughout sub-Saharan Africa fistula is seen as divine retribution for perceived sins. The consequences of this belief are extremely damaging to the women. As indicated by Roush, (2009) (24), many girls are divorced by their husbands and partners, disowned by family, ridiculed by friends and even isolated by health workers. Divorce rates for women who suffer from obstetric fistula range from 50% to as high as 89% (25). Furthermore, because the woman's ability to have children is impaired, she may be regarded as a source of shame to parents and other relatives. Friends are put off by the perceived curse, as well as the constant smell and discharge accompanying these women, this creates strongly self-stigmatising behaviour, show in **figure 14**, which in worse case, may lead to suicide. Fistula sufferers may be separated from their community and forced to live in isolation. They may have to resort to begging or stealing to survive (26).

Figure 13 Cartoon of stigma suffered by fistula patients

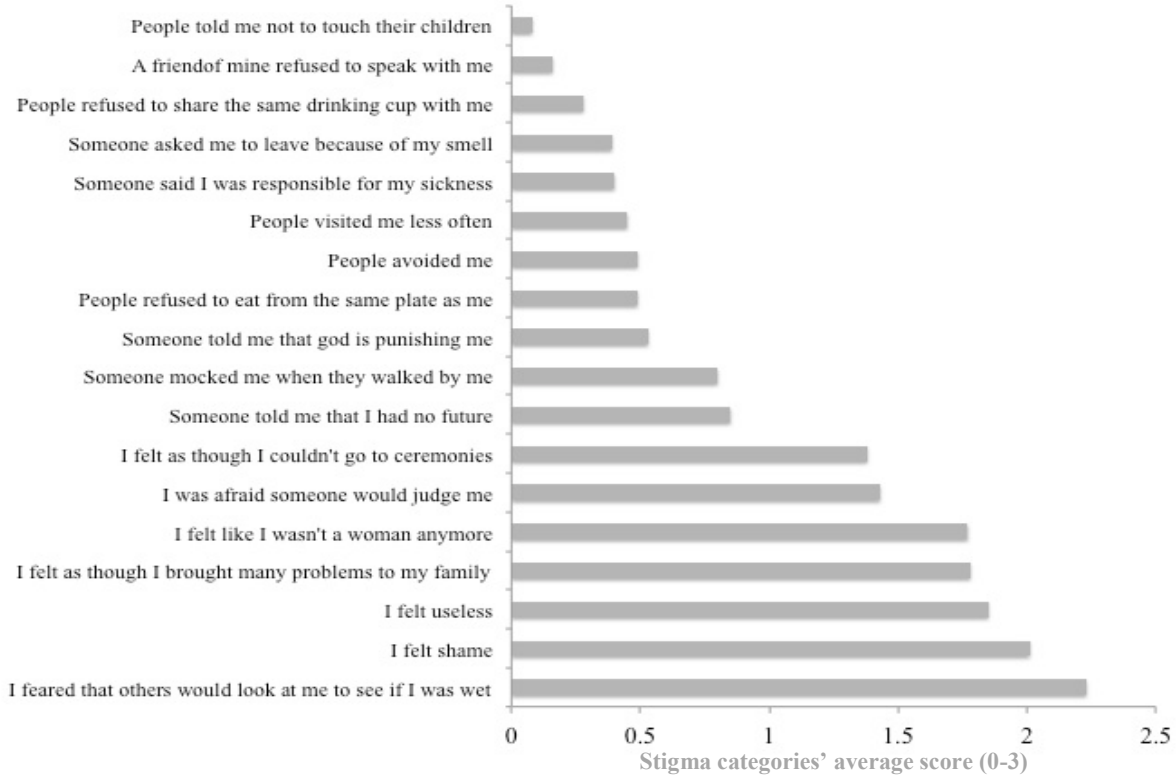

Figure 14 Chart depicting common stigmatising behaviours experienced by women suffering from fistula. Self-stigmatising behaviour is most common (52)

In many areas of Kenya, practices that make fistula more likely are common. These include female genital mutilation, child marriage, and eschewing modern medicine for traditional birth attendants. Further complicating matters is the very high prevalence of sexual assault in some areas.

Understanding the stigma surrounding fistula requires consideration of each of these factors. Female genital mutilation is illegal in Kenya; nevertheless the practice is highly prevalent in the north-eastern region, where over 90% of women are affected (27). This is largely due to the presence of the highly traditional, semi-nomadic Samburu. Whilst infibulation (the practice of excising the clitoris and labia and stitching together the edges of the vulva) was found by Browning (2010) not to be a causative factor of fistula (28), there is a correlation between the two, as areas with high FGM prevalence typically have high rates of child marriage, and low levels of literacy.

Child marriage is a causative factor; young girls have immature and under-developed pelvises, which often make birthing a full-size baby impossible (29). In Kenya, the UNFPA estimates show that child marriage is extremely prevalent, shown in **Figure 15** (30). Because early marriage and FGM are both illegal in Kenya, these young girls are unlikely to be taken for treatment. Fistula is rarely regarded as a curable medical condition in these communities, and these women may never receive treatment, even if the means are available to them. Even if treated, the social stigma often remains (31), as fistula is seen as a consequence of moral failings. Both FGM and child marriage are symptomatic of these communities' gender disparity. It has been postulated that one reason for the lack of care and extreme stigmatisation of these women is their low value to their community. An estimated 15% of wives are part of multiple wife households, and a man needs no justifiable reason to divorce a woman (27). Thus, the expensive surgery and rehabilitation, even if known, may be seen as unnecessary.

4.2 How can this be addressed?

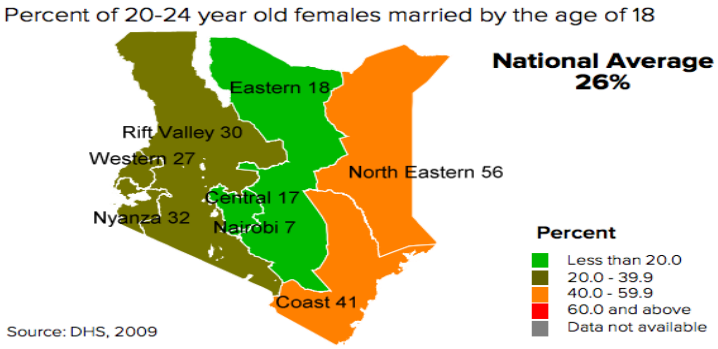

Figure 15 Child marriage rates in Kenya by sub-national regions. Eastern coastline shows the highest prevalence (30)

Ignorance and stigmatisation are often intertwined. Ignorance is the more easily remedied of the two. The primary means of addressing the stigma surrounding fistulas is therefore to increase the education of the community as a whole. Goals include:

- **Increased awareness** countrywide (particularly in rural communities and their healthcare services) of what fistula is, why it occurs, and that it is treatable. Such programs have been effective in increasing the proportion of fistula cases that are reported in Tanzania and Uganda, and have also assisted in reducing response time from referral to treatment.

- **Treatment of a greater percentage** of the estimated 3000 new cases that occur in Kenya each year (21) to minimise suffering of these women. In addition, the women who have been treated can spread information about fistula, correcting the misinformation surrounding the condition

- **Identification of women** living with fistula on a systematic basis, and evaluation of their living circumstances. Women living with fistula are at a greater than average risk of physical abuse, and are often in poor physical and mental health. The majority of fistulas go unreported; identifying them could save women from the crippling consequences of stigma and isolation.

To achieve these goals, it is necessary to implement practical and cost effective policies throughout Kenya, particularly in problem regions (see **Figure 15**), such as the Northeastern province.

Updating Curriculum

Education of healthcare providers is an easy way to decrease stigma associated with obstetric fistulas. The curriculum of midwives and surgeons could be updated and include a greater focus on fistula identification and prevention. A number of sufferers (32) have stated that local clinics failed to identify or treat fistula. If midwives were informed properly about the dangers of obstructed labour and fistula, they could then inform the women and communities they work with, as well as helping to identify women living with chronic fistula. Whilst this would require some investment on the part of the medical schools, it would not be extreme, and could produce measurable benefits.

A problem with these solutions is the mistrust of medical professionals displayed by many poor communities (33). An easy and cost effective way to circumvent this is to use the traditional birth attendants already in place within the communities.

Traditional Birth Attendant (TBA)

Figure 16 Josephine Achen, once a TBA and is now trained as a TBC, has been practicing in Uganda for over 30 years (59)

A TBA, figure 16, is someone who assists the mother during childbirth and initially acquired their skills by delivering babies themselves, or through an apprenticeship to other TBAs. They are often trusted members of the community and preferred to district health facilities due to their greater accessibility and affordability (12). According to the Kenyan bureau of statistics, in 2008/2009 only 44% of women in Kenya (including the main cities) delivered in a health facility (34), compared to 97.3% in England and Wales (35). However, the lack of formal training means that TBAs are too often unable to recognize the signs of obstructed labour and so cannot organize a timely transfer to a facility capable of performing a C-section and preventing an obstetric fistula.

Birth Attendants without official government training, such as TBAs, were outlawed in much of Kenya in 2011. However, the 2009 demographic health survey shows less than half of women deliver under the care of a skilled attendant in Kenya (36). 57% give birth at home with 28% assisted by a traditional birth attendant. In many traditional communities, it is considered imperative to give birth in the house of your husband, to prove the child's legitimacy (23). However this practice is often at odds with receiving skilled medical care. The Kenyan government's solution was creation of birth champions. These women were previously traditional birth attendants (37).

Training these attendants to become 'Birth Champions' (BCs), such as Josephine Acheo shown in Figure 16, and equipping them with basic medical training has allowed a greater degree of healthcare penetration into rural areas, whilst maintaining community trust (33). If training for TBAs was increased, with a segment on causes and treatment of fistula, the myths surrounding fistula may gradually be combatted. This would hopefully reduce the stigmatisation of fistula sufferers, as well as increasing the likelihood of them receiving treatment.

Education

Countrywide education could be implemented via media campaigns, such as those the Women and Health Alliance (WAHA) are running throughout sub-Saharan Africa. SMS campaigns, radio announcements, and community conferences are helping them to dissolve the social stigma of fistula (38). This can be supported and built upon by the Kenyan government, in the hopes of reaching those most at risk of fistula, as well as those who ostracise them. These campaigns could also advertise treatment camps such as those run by the UNFPA, and Gynocare (39). An ambitious side aim for these campaigns is increasing family planning. Whilst this would be difficult given the very religious nature of much of the country, if successful it would hopefully raise the mean age of primiparity, minimising risk of fistula and subsequent social isolation.

Figure 17 Photograph from Women and Health Alliance (WAHA) international fistula clinic (52, 21)

One of the highest cost initiatives possible would be to send out targeted treatment campaigns to rural areas. This involves sending out a small team of doctors and midwives to identify fistula cases and offer treatment. This may encourage others suffering in silence to come forwards, as more women realise that fistula is treatable, and not a punishment. Realising that fistula is treatable can combat the origins of the stigma regarding fistula: families are less likely to isolate women or to let them suffer. Each woman who is treated can then be re-integrated into family life and community life. However this initiative would likely require assistance from NGOs or similar organisations, as it would be difficult and require extensive, long-term funding. As previously discussed, incorporating this into other campaigns such as Fistula Fortnight would mean a shared service in delivery and would reduce costs, making it far more worthwhile.

5. REHABILITATION

Surgical repair + Social and economic rehabilitation → Empowerment + Independence

Post-operative rehabilitation is a key part of the recovery process in obstetric fistula treatment. Holistic approaches focus on the social, economic and physical wellbeing of sufferers. Whilst health services' recommendations for rehabilitation were most commonly counselling or health education, women themselves are most driven by returning to a concept of normality, a desire to return to their lives prior to fistula (40). This normality includes economic opportunity, returning to work or finding new means of generating income. This is linked to community perspectives on status and support, the ability to improve ones quality of life despite the disadvantaged and unfavourable starting position as a fistula sufferer. Lombard (2015) (40) suggests that policy makers must conduct broad action- oriented research, which focus on the needs of women after fistula repair from their own perspective. The power and independence gained from surgical repair combined with social and economic rehabilitation is a crucial part of helping these women repair their lives.

5.1 Foundation for Women's Health Research and Development (FORWARD) Project

Operating in the Kano State area of Nigeria, the FORWARD project provides pre and postoperative care for fistula sufferers. The central objectives of the project are to:

- Improve socio-economic status of women by increasing literary services
- Provide vocational training: develop and build skills for future job prospects

Isolation and change in lifestyle associated with obstetric fistula has negative impacts on women's mental health. A study of 70 fistula patients in Kenyatta National Hospital, Nairobi, in 2008 found 72.9% of women were suffering from depression, which was significantly associated with unemployment and a lack of support after fistula. Improving their socio-economic status is a practical and feasible way in which to help rebuild the social and community ties and transform women from outcasts to empowered literate individuals with an increased self-esteem.

Women stay at the FORWARD centre, see **figure 16**, for approximately 10 months. They are not seen as patients or sufferers while at the centre but as 'clients', demonstrating the esteem-building ethos of the project. Daily literacy and arithmetic classes are held along with income generating activities lessons. Literacy is a highly important skill, and is a key marker of national development. Income generating activities include

- Soap and pomade making
- Sewing and knitting
- Animal husbandry and livestock rearing

Upon graduation women are given a loan of raw materials needed for their future economic activities, which is to be paid back with 0% interest. There are many examples of FORWARD graduates returning to their home villages with higher status and greater empowerment. Some women renegotiate their marriages; some dissolve their marriages and marry men of their own choosing.

Policy makers are encouraged to integrate women's health, education, income productivity and community participation into coordinated sectional programs. The results seen at FORWARD are highly successful, and are recommended for replication in other Nigerian states and similar VVF projects in Africa.

Obstetric Fistula programs could also be highly successful in Kenya. There are similarities between Kenya and Nigeria in the national rate of postnatal visits and skilled birth attendants present at birth, both of which are factors shown to increase the diagnosis of obstetric fistula (16), see **table 2**.

Table 2 Comparison of antenatal care and skilled birth attendants in Kenya and Nigeria

	KENYA	NIGERIA
Antenatal care (5) 2008-2012 at least four visits	47.1	56.6
Skilled birth attendant at birth	43.8	48.7

Given some of the similar causes of obstetric fistula in Kenya and Nigeria, it is likely that implementation of similar projects would help to overcome the problems that fistula is responsible for, such as psychological trauma. Income generating activities, follow up appointments and social reintegration are central to the FORWARD projects, and therefore have the potential to be very successful in Kenya in rehabilitating fistula patients to a 'concept of normality'.

5.2 Teaching Mid-wives and Training Surgeons

A recent study (41) identified the main obstacles to timely obstetric care in Kenya as:

- Low attendance of skilled professionals at births
- Poor hospital care
- Preference for traditional birth attendants (TBAs)
- The rugged landscape
- Misinformation regarding birthing and its complications

Therefore, developing available facilities such as transport systems and midwives, as well as the general education of women, may be some of the best ways to develop targeted fistula prevention in Kenya. This targeted, country-specific approach is necessary when committing to lasting prevention strategies such as education: the same study found different major obstacles in Nigeria.

Education in prevention

Prevention is a less resource heavy way of reducing the fistula burden: improvement of emergency obstetric care is more basic than provision of specialised surgical treatment, which requires longer hospital stays and multiple post-operative check ups to be succesful (12). Therefore, prevention is better than cure.

However, the 'brain drain' of surgeons from rural district hospitals to private hospitals, large cities and other countries is a significant problem. Trainee surgeons are often sent to districts to 'fill the gap' but are insufficiently skilled, and not liable to stay (42), making continuity of care difficult. Further to this, many students are reluctant to take on the high workload, time heavy training for surgery. A Ugandan study (43) of students identified the reduced opportunity for research activity and lower pay than other routes as reasons for not entering the surgical profession. Incentives such as increased wage and benefits may help to remedy the situation, but many developing countries do not have this option available as a long term, viable solution.

Training and maintaining nurses and midwives

In some regions of Kenya there is severe understaffing: the Mwingi district was found in a UNFPA report to have 100 nurses where 200 were needed (12). The report also states that many rural facilities will have 1 nurse working when 4 or 5 are needed, with one nurse having not taken leave for 7 years.

Midwifery is a similarly understaffed profession (12). Their ability to detect obstructed labour early on and make the appropriate timely referrals if needed would lead to reduced fistula incidence as long as C-sections are made more available as above. However, similar problems as those existing in the surgical profession prevent women entering rural midwifery: it is not an attractive or easy lifestyle for many and the government isn't likely to have the ability to make it a more financially rewarding profession.

A potentially effective approach is one taken by the Hamlins of Ethiopia, who train midwives on four-year courses before deploying them back to their local area. This makes the midwives more trusted in a community with local dialects and traditions, and encourages the midwife to stay based where their family roots and friends are found. Allowing government trained midwives the option of choosing deployment to their home rural locations rather than placement to a far away district could have a similar positive impact in Kenya.

The "Advances in labour and risk management International Programme" (AIP) is a 5-day course including an obstructed labour module. It was taken by 80% of all professionals on an obstetric ward in a study (44) at the Moi teaching and referral hospital in Kenya. After the education course the percentage of emergency C-sections due to prolonged labour was reduced from 3.2% to 0.83%. This demonstrates the value of short courses that are cheaper and faster than training a new midwife or surgeon, as well as increasing the confidence of those dealing with emergencies, as staff were more aware of alternative ways to fix obstructed labour (44).

Further to this, a higher number of in-country surgeons would facilitate training of further students without the need for international interventions. However, developing this independence involves international help: the international federation of gynaecology and obstetrics (FIGO) has produced a standard handbook and competency based training programme currently being used by Action on fistula to increase the number of fistula surgeons in Kenya by 100% (45). Here, international expertise is being packaged in a helpful way to be distributed without the need for interested surgeons to travel extensively and expensively.

Mozambique Case Study – Technicos de Cirurgia

As a substitute for surgical training, current nurses receive a 3-year surgical course and graduate as "Technicos de Cirurgia", or TCs (42). Benefits of TCs include:

1. More experience than recent graduates sent to rural hospitals
2. They are able to carry out simple procedures, leaving more complex ones to trained surgeons.
3. 92% of C-sections and hysterectomies were carried out by TCs, increasing availability.

The introduction of TCs to Kenyan rural hospitals would increase the availability of C-sections; making prolonged labour less likely and reducing the risk of obstetric fistulas.

International responsibility

From an international point of view, certain surgeons and organisations possess the knowledge, which, if widespread and paired with the correct facilities, would benefit countless women in many places. Their responsibility is to disseminate the knowledge and support national governments in providing the necessary infrastructure for it to be used effectively and independently. Without the impetus of NGO initiation, government improvement of the situation would be slower, as they may need an external pressure to initiate change.

Interventions such as Fistula Fortnight were useful in that they reduced the caseload burden while training national surgeons and increasing interest in the public domain (8). A similar programme with an increased focus on training of surgeons, students and nurses would undoubtedly be beneficial to women suffering from fistula in Kenya, as well as attracting increased international support with the media spectacle of dramatic intervention. Alternatively, provision of opportunities for local surgeons to attend training at international centres would be a useful way of spreading the surgical expertise (4) and promoting interest.

5.3 Mental Rehabilitation

Often underestimated side effects of fistula are the mental health issues. These may occur after years of social isolation and pain, and perhaps immediately as a result of the loss of a child, which occurs in 85% of cases studied in one review (46). Whilst there is little empirical data on the subject, almost every written account of fistula includes details of anxiety, feelings of shame, and hopelessness. In extreme cases, these women attempt suicide. One woman treated for fistula in Kenya spoke thus:

> *"[Fistula] is a condition that denied me the chance to enjoy my life as a young person. I was isolated and rejected. All my nights were nights of shedding tears due to genital sores. I carried the condition for 12 years without knowing that I could be treated here in Kenya.... I made several attempts to take my life and was admitted to [a] mental ward… In May 2007 a successful surgery was done… The closure of that hole is not all that these women need. After I was operated on, I was returned to the mental ward again. You realise, I am not dead, but I am not living."* ***- Quote from a woman treated for fistula in Kenya (47)***

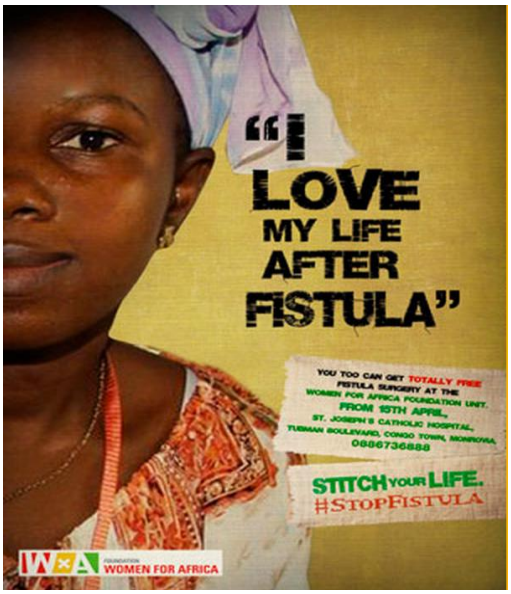

Figure 18 Campaign poster from MxA advertising fistula aid (58)

In a study conducted in Nigeria approximately 33% of women with fistulas were psychologically depressed, and an additional 51% were bitter about life (47). It seems intuitive that the longer these women live in isolation and shame, the more likely it is

that they will develop mental health problems. These women cannot work, pray, take part in a normal social life, or lead a normal married life within the community. In addition the vast majority of them will be young girls, grieving for a lost child. As such, surgery alone is unlikely to be sufficient to 'cure' a woman living with fistula. These women may have been outside of society for a number of years, often since they were very young, and may require assistance to regain their place in society.

A study in Eritrea showed that counselling can significantly improve self-esteem and should be used for social reintegration (48). A review of 10 other studies concluded that:

- 60% of the studies recommended assistance with resuming social roles was a positive rehabilitating factor
- 40% recommended counselling for family and friends to remove stigma (49)

In one village in the Northeastern region of Kenya, the population comprises exclusively of women who have largely escaped sexual violence and domestic abuse. Many of these women report that learning skills such as beadwork to generate income and become self-sufficient has given them a renewed sense of purpose, see **Figure 19** (50). Such skills can also help women to become accepted members of their community once more. Useful to this end would be microcredit social banks, as they could offer small loans to women who wish to start their own businesses (51). The church can also be a useful reintegration tool for these women. Providing them with someone to talk to and a community to re-join. One successful model for mental rehabilitation and societal integration was proposed by MSF (52). An interesting facet of this is group counselling with other fistula survivors. A large part of the mental suffering experienced by these women is as a consequence of isolation, both social and physical. Group counselling ensures that both within the hospital and after-release, the patients have a ready-made social circle of women with similar experiences to prevent further isolation.

As part of community education on fistula, with the chief aim of destigmatising the condition, the community could be

Figure 19 Umoja was founded in 1990 by 15 women who were raped by British soldiers. China Laprodati sits with her baby selling jewellery

encouraged to engage with patients both before and after treatment, to ensure they still feel as if they have a social role. This could be part of the role of the birth champions, who usually live in the same area as the women they help. However, the scarcity of empirical data available on the issue of fistula patients' mental health means that solutions will be devised largely on the basis of anecdotal evidence. Therefore their success cannot be reliably predicted. Nevertheless, it is imperative that this major facet of caring for fistula patients is not neglected. These patients suffer due to circumstances totally outside of their control, excruciating physical symptoms being only one side of this. The stress and grief of losing not only a child but effectively an entire social network, the terror of thinking they are cursed, and the daily loneliness of isolation all take a significant toll, and it is the duty of those who care for them to attempt to remedy this.

CONCLUSION

Obstetric fistulas are preventable and should no longer be prevalent in parts of the world like Kenya. However, there are currently two main hurdles to cross when reducing their prevalence: the lack of skilled professionals and available clinics, and stigmatisation. This policy paper provides suggestions on both how to increase the number of professionals and clinics, and reduce stigmatisation. The ultimate goal is to produce long-term, self-perpetuating solutions that do not require sustained international interventions. However, this begins with the integration of Foreign Agencies and the Kenyan Government. The foreign NGO can provide the initial funding, planning and resources that may not be available to the Kenyan Government. The responsibility of the Kenyan government is to improve their healthcare system comprehensively, by implementing policies and actions that improve fistula assessment and basic repair outcomes. A central 'Fistula Co-ordinator" should therefore be nominated in the Ministry of Health to oversee the integration of foreign agencies and the government. This integration should provide a solid grounding from which effective policies can spring off of. These policies should involve three key issues: collaboration, education and rehabilitation, all of which should be addressed cost-effectively.

For training and education, sending in an external, targeted team of skilled surgeons and midwives is effective but costly. Therefore, a more grass-root and efficient solution is the recruitment of obstetric and gynaecologist surgeons currently settled in rural practices. These surgeons could then be transported to inaccessible rural and urban areas using the mobile clinic, as constructing a new clinic immediately would be too expensive. If there were a lack of surgeons on the ground, as is likely to be the case in many rural areas, then the UNFPA's AIP intensive 5-day training course for TBAs would be the best short-term solution. Once more funding is available the government should invest in updating the curriculum for nurses and run 3-year surgical training programmes, such as those used in Mozambique to produce "Technicos de Cirurgia"(42). Training up TBAs to produce Birth Champions is important as they often well trusted within their community and it uses a structure already present.

Education through posters, SMS and radio announcements, as used by Fistula Fortnight, is an inexpensive and efficient way to raise awareness on obstetric fistulas. These should be addressed not just to the sufferer but also the entire community. The impact of discussing fistulas in such public spaces should not be underestimated: it reduces stigma by making fistulas less of a taboo topic; it signifies to sufferers that they are not alone, and shows there is somewhere for them to go seek help and rehabilitation.

Rehabilitation is key in improving the quality of life of the expected 30,000-300,000 current fistula sufferers in Kenya. Collaborative counselling of both the sufferer and their family and friends can greatly improve the sufferer's self-esteem. Engaging the community in education of fistulas also helps social reintegration when a woman returns to her community. However, to ensure these women are still valued in their society when they return, it is important to empower them by providing the means to produce income for their family. This is achieved through vocational skill development, such as animal husbandry, literacy and arithmetic classes, sewing and soap-making. The availability of microcredit and small loans is then integral to ensure the women have resources to start using these skills. For example, women graduating from the FORWARD Centre after 10 months are given loans and resource materials with 0% interest. They return to their communities with higher status and great empowerment.

Through the integration of Foreign Agencies and the Kenyan Government, new policies involving community collaboration, education and rehabilitation should become available to those at risk to and suffering from obstetric fistulas. The dissemination of information and trained surgeons using the Mobile Clinic is an inexpensive method of raising awareness and training TBAs into Birth Champions. This should increase the number of trained birth attendants. An improved salary and benefits from the government should mean the Birth Champions stay in their positions. Profits made by the government and NGOs through loans could then be used to build more clinics. Access to healthcare is improved through increased availability of clinics and trained surgeons and birth attendants. In turn, this should reduce prevalence of obstetric fistulas and provide more rehabilitation centres for those currently suffering. After enough local birth attendants and surgeons have been trained and clinics built, the prevention of obstetric fistulas self-perpetuates without the need for foreign agency involvement.

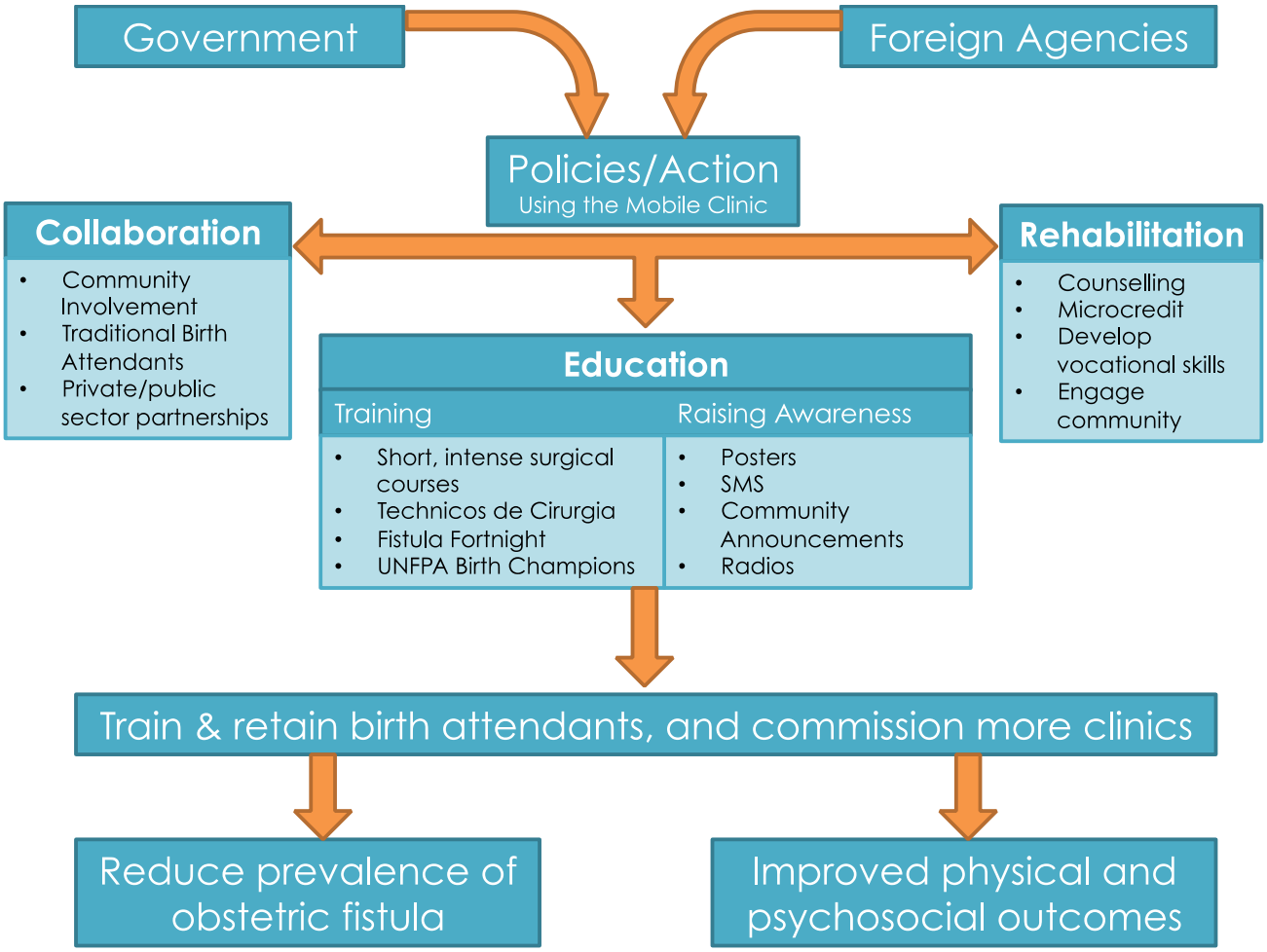

Figure 2013 Showing the steps the Government and foreign agencies can take together, addressing collaboration, education and rehabilitation. The overall aim being to train and retain birth attendants and eventually build more clinics. This should improve physical and psychosocial outcomes

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