

# MANAGEMENT OF OBSTETRIC FISTULA In Burundi

# THE EXPERIENCE FROM A MULTIDISCIPLINARY APPROACH OVER FIVE YEARS

MSF PROJECT IN GITEGA PROVINCE May 2016



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MSF-OCB MEDICAL DEPARTMENT

#### MANAGEMENT OF OBSTETRIC FISTULA IN BURUNDI

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#### **ABBREVIATIONS**

ARO	Annual Review of Operations
CURGO	Centre d'Urgences Gynéco-Obstétricale
CHUK	Centre Hospitalo-Universitaire de Kamenge
DHS	Demographic and Health Survey
EmONC	Emergency Obstetrics and Neonatal Care
GFC	Gitega Fistula Centre
GRH	Gitega Regional Hospital
GSF	Gynécologes sans Frontières
HI	Handicap International
HP	Health Promotion
IADH	Initiative d'Appui au Développement Humain Durable
FIGO	International Federation of Gynecology and Obstetrics
LuXOR	Luxembourg Operational Research
MMR	Maternal mortality rate
MDPS	Médecin Directeur de la Province Sanitaire
MSF	Médecins sans Frontières
MoU	Memorandum of Understanding
MoH	Ministry of Health
NGO	Non-Governmental Organisation
OF	Obstetric fistula
OCB	Operational Center Brussels
PNSR	Programme National de la Santé de la Reproduction
RVF	Recto-Vaginal fistula
TPR	Total Perineal Repair
UNFPA	United Nations Population Fund
USAID	United States Agency for International Development
VVF	Vesico-Vaginal fistula
WHO	World Health Organization



### EXECUTIVE SUMMARY

In 2009, Médecins Sans Frontières (MSF) set up Gitega Fistula Centre (GFC) within the Regional Hospital of Gitega (RHG), Burundi. Justification for the centre was underpinned by the high burden of obstetric fistula (OF) in Burundi and the absence of any national center dedicated to providing care and treatment for OF. The aim of GFC was to provide high quality, multi-disciplinary care, free of charge, all year round. This report aims to reflect on the MSF experience of setting-up, running and handing over a fistula project like GFC.

From the onset, creating sustainability was at the heart of the project, with innovation, knowledge transfer and lasting partnerships considered key. The deliberate choice to integrate GFC within the RHG added to the challenges of the project but was deemed essential for the hand-over of GFC to the HRG in 2015. By then, over 1500 patients had received surgical treatment.

Setting up GFC required heavy investment in terms of hospital infrastructure in order to establish a fully functional OF centre (including an OF surgical operating block, recovery rooms, patient wards, a waste zone and a fistula village with bedrooms, sanitary blocks, a kitchen and a recreational area). GFC provided multidisciplinary care which included pre- and postoperative nursing care, anesthesia and surgery, psycho-social evaluation and support, physiotherapy, health education, family planning, nutrition, and follow-up consultations. These services were all provided according to MSF standards and those of its close partner Handicap International (HI). One social worker responded to a countrywide free telephone "hotline" providing information on OF and the functioning of GFC.

From the start, training national doctors in OF surgery was recognized as an essential part of the project and the United Nations Population Fund (UNFPA) provided significant support for this. However, selection of capable and motivated trainees, and the introduction and use of a newly developed training manual by the International Federation of Gynecology and Obstetrics (FIGO), were not without their challenges. The only trainee, who reached the intermediate level and was eligible to work at GFC, became the Director of GFC after its hand-over. Unfortunately, her training was not completed hence close support from an expert surgeon remaining necessary.

To ensure a minimum case load of 20 surgeries per week, and to try to recruit a sufficient number of patients with a newly developed fistula for inclusion in a study on conservative (catheter) treatment, different outreach activities and strategies were developed and piloted:

- Active case finding through community OF screening remained a major part of the outreach activities during the course of the project, although it became much less effective over time likely reflecting the fact that the backlog of OF patients were treated, and the prevalence of OF dropped, hence there were less cases to be found.
- 2. More than 260 doctors, 1500 nurses and 3000 nursing students were trained to understand the causes of OF, diagnose OF patients and refer them to GFC. In order to overcome transport costs as a barrier for referral, innovative cost recovery systems were piloted, such as: transport vouchers, money transfer through mobile phones and direct reimbursement of the referring health center. The intention of these measures was to strengthen the referral system in a sustainable way.
- 3. Over 10,000 lay people were sensitized on OF and the function of GFC through participatory community gatherings. In addition, 230 cured OF patients were trained to

become fistula ambassadors, raising awareness on OF prevention and care in their communities. Mass media channels such as radio, TV and church assemblies were used to reach an even larger public.

Between 2009 and 2015, a total of 1559 patients were treated at GFC. As the project progressed, women began presenting much earlier following the development of their fistula, for example the proportion of patients with a vesico-vaginal fistula (VVF) less than one year old increased from 26% in 2010 to 84 % in 2015. Closure and continence rates at discharge following OF surgery were 77% and 61% respectively after the first intervention, and 58% and 41% after repeated interventions. For those women classified as "untreatable"- meaning that the OF could not be closed or that the patient remained severely incontinent after the final surgical attempt - social reintegration activities were provided by HI. These included support for the start-up of income generating activities and facilitation of re- integration into community networks. The average cost per patient treated (crudely estimated) was €2200.

In any given setting, the feasibility and relevance of setting up a fistula centre like GFC needs to be justified by sound data indicating a high prevalence and incidence of OF in that setting. In Burundi, MSF relied on the results of two studies conducted by the UNFPA to guide the implementation of its OF activities, particularly those related to the recruitment of OF patients. On reflection however, methodological limitations meant that the UNFPA data likely overestimated the incidence and prevalence of OF in Burundi and this had consequences related to resource allocation for MSF. In the absence of sound data, as is the case in most countries, planning an OF project needs to be based on proxy indicators such as maternal mortality and information on previous OF activity in the region. The use of a pilot fistula campaign in which close monitoring is established, might also allow essential information to be collected that more accurately informs a decision around the relevance of setting up a fistula centre.

Operational research was one of the main objectives of the OF project and several scientific papers were produced during the project (including several theses). However, the project was ill prepared to manage the large amount of data being gathered meaning that only part of the data was used or could be used. As such, there were lost opportunities with regards answering certain clinical questions, evaluating new treatment modalities and acquiring an in-depth knowledge on patients' profiles. Given the large knowledge gaps that still exist in terms of providing efficacious multi-disciplinary care for OF patients, it would seem important that efficient data collection and data management systems, carefully aligned with scientific lines of enquiry, are integrated into a program of this sort from the outset.

Lobbying and advocacy around OF, in order to put this forgotten disease on the agenda of policy makers and relevant partners, was an important component of the project and was instigated at various levels. At the national level, efforts were primarily focused on implementing a national strategy to prevent and cure OF (free of charge), with formal recognition of GFC being part of this. Unfortunately, at the time of handing-over GFC, decisions around a national strategy had yet to be finalized. At the global level, MSF took an active role in sharing and disseminating the knowledge it had gained in OF using various channels: a global multimedia campaign on maternal health, scientific publications, participations in worldwide OF platforms and presentations at international conferences.

Despite the challenges, MSF' experience in Burundi demonstrates that comprehensive OF care can be delivered in an efficient, affordable and to a certain degree, sustainable manner. It is hoped that health authorities, MSF and respective partners will be able to apply the results of this report to improve OF care for those women still in need of life changing treatment.

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# CENTRE "URUMURI" POUR LE TRAITEMENT DES FISTULES OBSTETRICALES

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## **1. INTRODUCTION**



#### **1.1 BACKGROUND**

Since 2007, Médecins sans Frontières (MSF) has been providing care and treatment for obstetric fistula (OF) as part of its reproductive health care package. Various models of OF care have been developed and implemented by different MSF sections, ranging from periodical fistula camps focused mainly on surgical treatment, to permanent fistula centers providing multidisciplinary care and long-term follow-up of patients<sup>(1)</sup>.

In November 2009, the MSF-Operational Center Brussels (OCB) set up a dedicated fistula facility in Gitega, Burundi, called Gitega Fistula centre (GFC) – the only permanent facility in Burundi to specialise in OF management. GFC was established within the Gitega Regional Hospital (GRH) – a Ministry of Health (MoH) structure – and provided a package of comprehensive activities, combining high quality care and innovation, through operational research. After treating 1559 patients, GFC was handed over to GRH in August 2015.

#### **1.2 OBJECTIVES OF THE REPORT**

The purpose of this report is to reflect on the MSF experience of setting-up, running and handing-over a fistula project like GFC. It focuses on the challenges encountered, the lessons learnt and the achievements accomplished. For a more detailed technical description of GFC and its outcomes, please refer to the final project report<sup>(2)</sup> and the "Toolkit" developed by the Sexual and Reproductive Health working group<sup>(3)</sup>. Note: This report does not cover the treatment of 86 patients with other pathologies than OF (eg: urinary incontinence without fistulae, complications after caesarean section or advanced cervical cancer).

#### 1.3 CONTEXT/HISTORY OF OBSTETRIC FISTULA CARE IN BURUNDI

MSF-OCB has been present in Burundi since the start of the civil war in 1993 and had been involved in supporting health services, delivering trauma care and responding to various emergencies. Sexual and reproductive health have always formed a core part of MSF-OCB's activities in Burundi: from 2003 until 2009, MSF-OCB treated victims of sexual violence at the Seruka Center, which was subsequently handed over to a local NGO created by ex- MSF national staff members; in 2008, MSF-OCB opened an emergency obstetric and neonatal care (EmONC) facility - Centre d'Urgences Gynéco-Obstétricale (CURGO) - in Kabezi district to address the serious lack of adequate referral facilities for EmONC in the province of Bujumbura Rural. The center was handed over to the MoH in 2013.

Burundi has a high maternal mortality rate (MMR), (808 per 100.000 live births in 2010) with an annual reduction of 2% between 2000 and 2015<sup>(4)</sup>. A high MMR is associated with high maternal morbidity, OF being one of the most severe of these. OF is preventable by timely caesarian section in the majority of cases. Although the World Health Organization (WHO) recommends that the caesarian section rate should be between 5 and 15% of all deliveries, Burundi's caesarian section rate was only 3%; this implies a high risk for OF.

In 2006, a study by the Program National de la Santé de la Reproduction (PNSR) and the United Nations Population Fund (UNFPA)<sup>(5)</sup> estimated the incidence of OF in Burundi to be 1200 per year. A more recent UNFPA study conducted in 2013<sup>(6)</sup>



estimated a national prevalence of 3500 OF cases and an incidence of 750 OF cases per year. The 2006 and 2013 prevalence studies however were limited by small sample sizes<sup>(7)</sup>.

In 2003, the UNFPA started a worldwide campaign to end OF<sup>(8)</sup>. In 2012, the UNF-PA appointed an OF focal point in an effort to intensify, coordinate and support all OF activities in the country.

Since 2010, the MoH had undertaken various steps, in line with the UNFPA strategy, to 1) develop a National Strategy for Obstetric Fistula Prevention and Cure and 2) create a National Referral Centre for fistula surgery. To date, both objectives however are yet to be formalized.

From 2005 onwards, the head of the Department of Obstetrics and Gynecology at the Centre Hospitalo- Universitaire de Kamenge (CHUK) in Bujumbura - the only doctor trained in basic fistula surgery - organized one to three fistula campaigns per year in collaboration with different partners: PNSR, UNFPA, Gynécologes sans Frontières (GSF), Handicap International (HI), Coopération Pays de la Loire-Burundi, and Médecins du Désert (MDD).

In January 2009, MSF-OCB created a twoyear position for an obstetric fistula referent at its headquarters with the aim of increasing the volume and quality of OF care, according to operational objectives<sup>(9)</sup>. In August 2009, MSF-OCB implemented its first fistula camp at CURGO and this was followed by the opening of a permanent multidisciplinary OF Center in Gitega<sup>(10)</sup> in 2010.

#### 1.4 JUSTIFICATION OF THE PROJECT

Justification for opening a permanent multi-disciplinary OF Center in Gitega was based on the following considerations:

- 1) The high prevalence of OF in Burundi
- 2) The high MMR indirectly indicative of a high incidence of OF
- The absence of any formal provision of OF care and treatment prior to 2005 and the long period of civil war (implying a substantial backlog of OF patients)
- A long waiting list of OF patients compiled by the Head of the Department of Obstetrics and Gynaecology at CHUK
- 5) The low level of fistula repair activity in the country (50-60 interventions per year at CHUK, and very small numbers of repairs at the Ngozi Hospital and a few other facilities)
- 6) The limited level of OF surgical expertise in the country
- 7) The absence of a permanent fistula center where multidisciplinary OF care

and follow-up was offered and quality research could be conducted

- The identification of GRH as a centrally located MoH structure willing, on paper, to integrate fistula repair activities in the hospital
- The presence of activities at CURGO covering the preventive part of obstetric fistula
- 10) The presence of several potential partners already active in OF care
- 11) The significant life changing potential of treating a woman with OF

#### **1.5 PARTNERSHIPS**

MSF seldom engages with multiple partners when implementing its projects, however, right from the onset of the OF project in Gitega, various essential short and long term partnerships were established.

#### 1.5.1 INTERNATIONAL NON-GOVERN-MENTAL ORGANIZATIONS (INGOS)

- Handicap International (HI): Partnered with MSF in 2009 and was involved for almost the entire duration of the OF project. Embracing the vision that OF is a "handicap", HI's specific focus in relation to OF care was on: transport of patients, psycho-social support, including follow-up service and social reintegration through their "Projet les femmes de l'Arrière Court"<sup>(11)</sup>. The extent of their involvement depended largely on annually received funds.
- 2) GSF: Initiated fistula surgery at CHUK in 2005 and developed a long term program in gynecological surgery at the REMA Hospital in Ruyigi. In 2013, a formal partnership was established to cover the surgical treatment of patients with severe uterine prolapse as a high proportion of uterine prolapse cases were found during the OF recruitment activities.



- MDD: MSF-OCB assisted in the recruitment and postoperative care of OF patients treated at a fistula camp carried out by MDD at CHUK in 2012.
- Gruppo di Volontariato Civile (GVC): Was involved in maternal health in Bujumbura Rural province and supported the recruitment and transport of patients during the first fistula camp at CURGO.

#### 1.5.2 NATIONAL NGO'S

- Shujaa Link, in partnership with HI, assured the presence of professional care takers at GFC from 2009 until 2013.
- "La Croix-Rouge Burundi" and "Initiative d'Appui au Développement Humain Durable" (IADH) were involved in various health promotion (HP) activities that took place in Makamba province.

#### 1.5.3 MOH AND UNFPA

In 2009, MSF-OCB joined a national platform in Burundi uniting most fistula actors. It was initiated by the UNFPA and led by a PNSR representative, with the aim to develop a national program to prevent and cure OF. The output of this platform however was very poor. The MoH insisted on full integration of the project in a MoH structure but provided very little support initially to facilitate this process. A Memorandum of Understanding (MoU) was signed for three years between MSF-OCB and GRH to assure the integration of OF activities within the hospital, and this was then renewed for another three years. It was only at this stage, with the arrival of a new Director of the Hospital, that MoH engagements were well respected and had a significant impact on the integration and hand-over process.

In April 2013, a MoU was signed between MSF-OCB, UNFPA and the MoH mainly covering the training of two national doctors in fistula surgery<sup>(12)</sup>. This MoU was also an important step to securing the involvement of the UNFPA after the hand-over of GFC from MSF to the MoH.



### 2. GITEGA FISTULA CENTER -A MULTIDISCIPLINARY OBSTETRIC FISTULA CENTER

#### **2.1 INTRA-MURAL ACTIVITIES**

#### 2.1.1 INFRASTRUCTURE

Although not anticipated at the start of the project, the infrastructure at GRH was in a poor state of repair and as such MSF had to invest heavily to obtain the minimum MSF required standards for a surgical project. In addition to the initial construction works, MSF continued rehabilitating the infrastructure up until the end of the project.

#### CONSTRUCTION/REHABILITATION

 Surgical block: a fistula operating theatre (OT) was established in an empty room located between the two existing OTs. Dedicating this OT entirely for OF repair ensured that there was never interference from other surgical activities or emergencies.

In the absence of a recovery room, a new one was built.

The sterilization room needed complete redesign and rehabilitation to allow a proper circuit.

At a later stage, the two main OTs and adjacent rooms were also rehabilitated and equipped to obtain a minimum standard for the whole operation block.

- 2. Laundry services: completely rehabilitated.
- Fistula ward: a free standing ward of 14 beds with two consultation rooms



was completely rehabilitated. Outdoor corridors connecting the surgical block and the wards were roofed over in time.

4. Fistula village: a village for women admitted to GFC was newly constructed in a corner of the hospital compound.



It comprised four wards of 12 beds, a sanitary block, a kitchen, a storage room, a laundry and drying area, and an open meeting place. At one stage of the project, the wards reached capacity and a large hospitalization tent and several smaller ones were erected to accommodate more women. These were associated with serious hygienic problems however and were therefore replaced by semi-permanent structures.

- 5. Administrative building: an empty building next to the village was rehabilitated as an administrative building.
- 6. Pharmacy and physiotherapy room/ overflow ward: these were installed in an adjacent hospital building following minor rehabilitation.
- 7. Waste area: complete reconstruction in different phases.
- 8. Meeting room: this was constructed for use by MSF and MoH staff.

There were two major challenges regarding the rehabilitation of the hospital infrastructure and its utilization:

- Is it unethical to create within the same structure optimal conditions for one patient group, the fistula patients, while ignoring the others? An affordable and acceptable compromise was found.
- How to assure compliance with MSF protocols (e.g. universal precautions) in a project involving MSF and non-MSF (MoH) staff? Close collaboration between a motivated hospital Director and the MSF team rendered this possible, as demonstrated at the end of the project.



#### 2.1.2 MULTIDISCIPLINARY PATIENT CARE

#### NURSING

During the pilot-phase of the project in April 2010, hospital staff was designated to work at GFC, as stipulated by the MoU, without being put on the MSF pay role. Unfortunately, this did not work out, because they were not paid, and early on in the project, all hospital staff was replaced by MSF staff. Only towards the end of the project, when the hand-over was in sight, was a small nursing team successfully assigned to work at GFC, paid for by the hospital.

#### SURGERY/ANESTHESIA

All eligible patients were operated on by highly qualified fistula surgeons or by supervised trainee doctors or surgeons. In the absence of evidence-based guidelines on OF surgery, and the fact that each surgeon preferred their own protocols and surgical approaches best, a "common sense approach" was used; standard surgical MSF protocols were regularly adapted (e.g. antibiotic prophylaxis, use of specific sutures, length of ureteric catheterization, etc.). Other practices (e.g. vaginal versus abdominal approach, bowel preparation, etc.) were left to the discretion of the individual surgeon. This approach demanded a high flexibility from the staff, but did not seem to compromise the quality of care provided.

The majority of cases where operated on under spinal anesthesia, performed by national anesthetic nurses. Due to the high turn-over and/or lack of experience of these nurses in fistula surgery, continuous training and close supervision remained necessary throughout the program.

#### MEDICAL CARE

Following surgery, patients were monitored for complications on a post-operative ward by qualified nursing staff. There was no intensive care unit available but IV fluids with or without medication, parental feeding and oxygen could be administered on the ward as needed. Only simple laboratory tests could be performed on site using rapid diagnostic tests (e.g. haemoglobin, blood sugar levels, urine protein and blood group). Standard imaging (X-rays) and a blood bank were only available at GRH during the second half of the project. Patients with severe medical conditions (e.g. acute kidney failure, ongoing sepsis of unknown origin, suspicion of severe electrolyte disturbance) were referred to a tertiary level hospital in Bujumbura, two hours' drive from Gitega.



#### PHYSIOTHERAPY

Although there are no evidence-based guidelines on physiotherapy as part of treatment for OF, group sessions were used to teach women pelvic floor strengthening exercises. Individual patient tailored physiotherapy was also provided as needed. In addition, based on encouraging findings from a study done in Benin<sup>(13)</sup>, HI supported the introduction of the following innovative techniques and tools at GFC: low pressure abdominal exercises, an adapted urinary incontinence scale, the Ditrovie- Quality of Life Scale and, later on in the project, biofeedback and electrical nerve stimulation. A national physiotherapist and other staff members were trained in the use of these new techniques and tools. Unfortunately, the effect of these innovative therapies could not be measured because of poor data collection and incorrect use of the equipment by the local physiotherapist<sup>(14)</sup>. This could have been avoided through better planning, training and close monitoring as part of an approved operational research protocol.

#### PSYCHO-SOCIAL SUPPORT AND EDUCATION

Every patient received at least four individual psycho-social consultations/education sessions during their hospitalization: 1) assessment of their social status at admission, 2) pre-operative consultation, 3) family planning consultation and 4) pre-discharge consultation. These were provided by two full-time national social workers. Group counselling and education on OF were part of the routine activities, together with peer support activities (such as singing, dancing and craft work) to build solidarity and restore self-esteem among the women.

To reduce the burden of transporting, lodging and feeding family care takers, four professional care takers (one per 12 patients) were recruited through the NGO, Shujaa Link, to look after the women. This innovative arrangement was well accepted by patients and their families. Family members could visit patients when they wanted and there was a free telephone hotline for patients to stay in touch with family members. The only disadvantage with not having family members staying on site was the absence of husbands and other family members when discussing how to ensure a complete recovery at home (e.g. abstinence of sexual intercourse, family planning, follow-up visits).

#### FAMILY PLANNING

To allow complete wound healing, OF patients are recommended to abstain from vaginal intercourse for up to three months postoperatively. The MSF-protocol<sup>(3)</sup> also recommends that OF patients use a safe family planning method for at least 12 months, although this recommendation is not evidence-based which raises some questions around its relevance. At GFC, adherence to family planning beyond at three months dropped from 95% (2011) to 44% (2015).

#### NUTRITION

Patients received three high quality meals per day prepared by the care takers and patients themselves in the kitchen at the fistula village. This required a substantial and continuous logistical effort. Capable patients were encouraged to help with the cooking as a social activity. Malnutrition was rare among OF patients admitted to GFC, except in those patients referred from other hospitals with long standing sepsis (often after a complicated caesarian section). Surgery was postponed in such cases until the nutritional status had been optimized.



#### FOLLOW-UP

Most fistula projects lack a systematic follow-up system. At GFC, follow-up telephone calls by the social worker were scheduled at 3- and 6-months after discharge to assess continence and psychosocial status (using the Ditrovie Incontinence and Quality of Life Scale). Follow up using telephone calls was introduced after study results showed high rates of loss-to-follow-up among women asked to return to the center in the first year after discharge<sup>(15)</sup>. Loss-to-follow up was significantly reduced after the telephone-based follow-up approach was implemented. If a patient complained of a specific medical problem, they were asked to come back to GFC to be medically assessed. Patients needing prolonged assistance with social reintegration were referred to HI or local associations

#### 2.1.3 SURGICAL TRAINING

In 2011, the International Federation of Gynecology and Obstetrics (FIGO) developed a fistula surgery training manual<sup>(16)</sup>, covering three levels of surgical proficiency: basic, advanced and expert level. MSF has been using this manual since 2013.

At GFC, one of the main objectives of the project was to train one Burundian doctor per year in fistula surgery, in order to build national capacity for OF repair. This was a major challenge for various reasons outlined below:

#### 1. Recruitment of appropriate trainees

Not only did it take 12 months for the MoH to assign a trainee to GFC, but on account of the trainee's limited surgical experience, suboptimal motivation, together with lack of a formal structured training program, the 12-months training failed.

It was not until 2013, that two new trainees were recruited, this time after applying strict recruitment criteria as part of a MoU between MSF, MoH and UNFPA<sup>(12)</sup>. The first of these trainee doctors completed the basic training but was excluded from longterm engagement in a MoH hospital on account of not being a Burundi nationality. Fortunately, her skills have not gone to waste and she currently operates on small numbers of patients with uncomplicated OF in the private REMA hospital in Ruyigi.

Training of the second recruit was delayed due to private circumstances. She became the Director and surgeon of the fistula unit at GRH after GFC was handed over. The concern however, is that she has never reached the advanced level of surgery needed to treat patients with complicated OF, the likes of whom make up the majority of OF patients at GFC.

Towards the end of the project, two doctors from GRH bypassed the recruitment procedure and joined the OF training program "unofficially" after being recommended by the MoH and the Hospital Director. This resulted in that one doctor left and the other doctor continued his training with UNFPA support.





#### 2. Availability of trainers

The high-turnover of expert surgeons, each with their own surgical approach and capacity as a trainer, meant that the training program was not standardized and as such less efficient. That said, introduction of the FIGO Training Manual did help streamline the training.

It was no small feat for staff at OCB Headquarters to establish a pool of OF experts/ trainers (eight in total, five based in Africa) but fortunately major gaps during the project cycle at GFC were avoided. Between 2010 and 2012, eight expatriate surgeons were trained at GFC. Due to the limited training time available however, only two reached the advanced level and none the expert level. None of these trainees was therefore ready to join the pool of trainers, contrary to what was initially planned for.

#### 3. Certification of trainers and trainees

At the time of the project, there was no formal certification process for OF trainers and as such several of the trainers felt not qualified to certify the trainees themselves. FIGO is currently in the process of certifying trainers and training centers however.

#### 4. Availability of patients

The majority of patients presenting at GFC had complicated fistulae and were not suitable patients to be operated on by the trainees. Inadvertently, this seriously prolonged the period of time needed for trainees to gain sufficient hands-on OF surgical training.



#### **2.2 EXTRA-MURAL ACTIVITIES**

#### 2.2.1 RECRUITMENT OF PATIENTS

Setting up a fistula centre is only beneficial if a continual influx of patients can be assured, and at the same time, if the influx of patients matches the pace of the surgeons. At GFC, this equilibrium was more or less achieved and 20 operations were typically performed per week.

To facilitate access to GFC, GRH was deliberately chosen as the site for the centre based on the fact that Gitega is located in the geographical center of the country. Fortunately too, Burundi is a small country with a well-developed road network linking prominent parts of the country.

Seldom described, recruitment of women with OF was a key part of the MSF OF project and one of the most resource demanding activities. From the start of the project, MSF mobile teams were sent out to MoH health structures in all provinces to recruit OF patients. As this type of nationwide OF outreach activity had never been undertaken before, different strategies were piloted and adopted over the years, all with their strength and weaknesses<sup>(17,18)</sup>. Two health promotion/outreach pilot projects (Kirundo province, 2012 and Makamba province, 2013) were implemented in order to cover the following activities: prevention of OF, recruitment of fresh fistula patients and setting-up of a sustainable

referral system of OF patients to a central specialized center.

#### 2.2.1.1 Mobile teams over time

2010-2011: GFC team performed periodical recruitment sessions according to a pre-defined agenda

2012-2013: two dedicated outreach teams - one for adapted periodical recruitment sessions and the other for the pilot projects mentioned earlier.

2014: the above mentioned teams merged as one team and continued performing the same activities described.

2015: outreach activities ceased due to increasing insecurity and low patient recruitment rates.

#### 2.2.2 ACTIVITIES

#### 2.2.2.1 Active Case finding

Community OF screening sessions for women with OF symptoms were organised at specific health structures in different provinces throughout Burundi. To encourage attendance at these sessions, specific messages were broadcast extensively two weeks prior to the sessions by way of radio, churches, administrative (village) leaders and staff at surrounding health structures. Women attending these sessions were screened, examined, informed of the findings, referred in case of other gynecological problems (in particular for severe uterine prolapse), and selected for surgery if found to have a fistula. A provisional date of admission to GFC was scheduled and transport arrangements made. Simultaneously, the consultants at that particular health structure were trained in OF diagnosis.

Over time, the community screening strategy was re-orientated in terms of target locations from centralized province level structures (provincial hospitals) to decentralized health center level structures. Health centers with particularly low or high recruitment rates were targeted.

Active case finding was by far the main source of patient recruitment in the first few years of the project, becoming less effective towards the end.

#### 2.2.2.2 Referral system strengthening

At the start of the project, health structure referrals to GFC were low, suggesting that public healthcare staff in general had limited OF-related knowledge and limited awareness about GFC and the way it functioned. In line with the substantial health promotion efforts undertaken by the mobile teams, the number and quality of referrals steadily increased over time. Referrals for "fresh fistula" patients (150 in total) also increased, further supporting the role played by HP activities in facilitating health structure referrals. By 2014, the number of patients referred from health structures exceeded the number of patients recruited through active case finding activities (cf results section).

According to the MoH's global health policy, patients with obstetric complications, including OF, should benefit from free transport and free treatment at a referral center integrated within the existing national referral system. In practice, most MoH structures were unable to provide transport in the first place and public transport costs remained a barrier to accessing treatment at GFC. To overcome this challenge, GFC initially introduced transport vouchers and later implemented a reimbursement system at the health centers and also through mobile phones. Although innovative, the two latter approaches did not have the anticipated result.





#### 2.2.2.3 Improved access to information

In some fistula centers<sup>1</sup> that have been providing high quality care for decades, almost all OF patients are self-referred. Despite considerable efforts to encourage self-referral (see below), the majority of patients at GFC were either recruited through active case finding activities or referred by a health care provider. Nonetheless, community awareness was raised in the following ways:

#### 1. Health Promotion (HP) activities

An impressive 10,000 people were reached at the community level through participatory community gatherings about OF.

Traditional birth attendants/traditional healers were specifically targeted in Kirundo province with the objective of identifying patients with fresh fistula and preventing OF. The results of this initiative however were not satisfactory and as such an adapted strategy (based on an internal evaluation<sup>(19)</sup>) was implemented in Makamba province:

 a) Involvement of the Red Cross Society: They have an extensive network of active volunteers and the volunteers were trained to recognize OF patients as "vulnerable people", in line with their modus operandi.

- b) Mobilisation of the community health workers network: Using an existing performance based reward system, community health workers were taught to identify potential OF cases and refer them to the health centers.
- c) The introduction of OF ambassadors (see below).

#### 2. Fistula Ambassadors

During the course of the project, 230 cured patients were trained to become 'fistula ambassadors' and to communicate basic information on OF prevention and care back in in their home communities. All expressed a strong will to act as first hand witnesses and also demonstrated capacity to speak in public. Their core messages covered: stigmatization, the availability of free care at GFC and the importance of seeking care as early as possible. They underwent their first training session at GFC, followed by two follow-up sessions in their home environment carried out by the project's mobile teams.

#### 3. Mass media

Journalists for various newspapers, radio and television stations were invited to key events at GFC (the opening of GFC; an occasion marking one thousand interventions; International Women's Day; International Day to end Obstetric Fistula; and the project hand-over). Additionally, MSF reserved regular time slots on national and local radio to broadcast OF-related messages (in different local languages), describing the symptoms of OF, announcing the arrival of the mobile teams for screening, drawing attention to the existence of the free OF telephone hotline number, and highlighting the availability of free-ofcharge OF care at GFC. The existing national medical radio program also covered OF-related issues regularly and listeners were invited to call in for questions. In 2014, HI produced a TV soap series about an OF patient admitted at GFC.

#### 4. Telephone hotline

In 2011, a countrywide free telephone "hotline" was installed with the support of HI. Through the above mentioned promotional activities, potential patients and health care providers were encouraged to call the hotline to obtain OF-related information and advice. A structured questionnaire was used to identify possible cases of OF over the phone and in such cases, the woman was asked to come to GFC. In 70-80% of women who came to the centre following a telephone consultation, an OF was confirmed. The hotline received on average 10-15 calls per day,



although half of the calls were unrelated to OF enquiries.

#### 5. Other means

Leaflets, T-shirts, umbrellas and posters displaying essential information (hotline number, availability of free care at GFC) were distributed all over the country.

#### 2.2.2.4 Social reintegration

The psycho-social status of the patient was recorded at admission and at the 3 and 6 month follow-up checks carried out by the social assistant using the Ditrovie incontinence and Quality of Life Scale. These data are yet to be analyzed as part of an ongoing study examining the effect of fistula repair on quality of life. Additionally, socio-anthropological research would have been beneficial for gaining a better contextual understanding of the impact of OF on peoples' lives.

From the start, the project focused on the social reintegration of women classified as "untreatable", meaning that the fistula could not be closed or the woman remained severely incontinent even after surgery. A HI social worker conducted home visits for such women in order to facilitate income generating activities and encourage integration into community networks such as women's groups, village elder support groups etc. Unfortunately, specific data on the number of women who were engaged in this way, the type of assistance provided and the outcomes of this initiative are not available.

### 2.2.3 TRANSFER OF MEDICAL KNOWLEDGE

Between 2010 and 2015, over 260 doctors, 1500 nurses and 3000 nursing students (in their respective schools) were given OF training by MSF staff. Trainings were often organized during patient screening/recruitment visits, and provided theoretical and hands-on training at the health workers' place of work. Trainings were adapted to the knowledge level and responsibility of each group. Emphasis was on OF diagnosis, referral, immediate catheter treatment, timely referral of patients with a fresh fistula, and the function of GFC. In 2015, a specific training targeting all the 17 medical provincial directors (MPDs) was conducted in order to prepare and encourage the MPDs to take a more active role in referral after the hand-over.

#### 2.3 DATA MANAGEMENT

A large amount of data were gathered and entered in several data bases:

- Surgery/anesthesia data base
- Hospitalization data base

- Social assistance/follow-up data base
- Physiotherapy data base

Except for the surgery/anesthesia database, which is a standardized database used in all OCB surgical projects, all other databases were designed and adapted over time specifically for the OF project. The implication of this was that the quality of the data gathering and data encoding was not systematically monitored. Data capture on patient profile, physiotherapy, morbidity and mortality in particular was weak and this was only recognized late in the project, jeopardizing in-depth analysis.

Patients were classified as new or old cases. New cases were those patients who presented at GFC for the first time, irrespective of whether they had received an OF intervention elsewhere; old cases were those patients whose OF could not be closed in one single attempt at GFC and who were re-scheduled for a follow-up intervention post-discharge. Total cases were therefore not equal to total patients. Similarly, total number of fistulae was not equal to the total number of patients, as one patient could have more than one OF.

Treatment outcomes were determined at three different times:

- At discharge from GFC: The dye test was done to clinically confirm fistula closure and standard questions asked to determine continence status. Only patients who denied any leakage of urine and/or faeces were considered continent. Treatment outcomes were classified as follows: closed fistula and no incontinence, closed fistula with residual incontinence, and fistula not closed. These outcomes were determined by the medical doctor.
- At three and at six months follow-up: fistula closure and continence status were re-evaluated by telephone. If a patient reported any problem, they were asked to return to GFC for a medical examination, including a dyetest.

#### **2.4 OPERATIONAL RESEARCH**

Operational research was one of the main objectives of the project. For the period



2010-2011, the Innovation Fund of MSF International allocated € 250,000 for the study of early catheter treatment of OF(20)

The national Medical Director of GFC (2011-2014) received MSF training in operational research. The Medical Coordinator (2012 -2014) was already part of the Luxembourg Operational Research (LuXOR) team before. Both are (co) authors on the following research studies conducted at GFC:

1. Conservative management of fresh obstetric fistula in Burundi: Where are the patients? van den Boogaard W. et al, MSF-OCB and Luxor, 2013(20)

In the early stage of the study, two principal investigators left MSF. A second problem was the very low rate of patient recruitment. Review of the recruitment strategy by the LuxOR team boosted outreach activities and resulted in an accelerated recruitment rate. A total of 122 patients were included in the final study. Intermediary results were presented during the MSF-OCB scientific day (orally) and the MSF-UK Scientific Day (poster) in 2013. The final results were presented at the ISOFs bi-annual conference in Kampala, Uganda, October 2014. Write-up of the full article is still ongoing.

2. Tayler-Smith K, Zachariah R, Manzi M, van den Boogaard W, Vandeborne A, Bishinga A, De Plecker E, Lambert V, Christiaens B, Sinabajije G, Trelles M, Goetghebuer S, Reid T, Harries A. Obstetric fistula in Burundi: a comprehensive approach to managing women with this neglected disease. BMC Pregnancy Childbirth. 2013 Aug 21;13:164.(21)

- 3. Bishinga A, Zachariah R, Hinderaker S, Tayler-Smith K, Khogali M, van Griensven J, van den Boogaard W, Tamura M, Christiaens B, Sinabajije G. High loss to follow-up following obstetric fistula repair surgery in rural Burundi: is there a way forward? Public Health Action. 2013 Jun 21;3(2):113-7.(15)
- 4. Quality of life in relation to continence status of women following obstetric fistula care in Urumuri Centre, Gitega Regional Hospital, Burundi. This study has been finalized but is still in the manuscript write-up phase.(22)

Two authors, not employed by MSF, used the GFC data to write their theses:

- 1. Van Wolvelaer, Pieter F.S. Obstetric Fistula Program in Burundi, a retrospective descriptive longitudinal study. Master of Science in Public Health Thesis, Institute of Tropical Medicine, Antwerp, July 2014<sup>(18)</sup>
- 2. Nahaniiyo, Consolata. Contribution à l'amélioration de la prise en charge de la fistule obstétricale au Burundi: cas de Centre Urumuri. Mémoire de Diplôme d'études supérieures en gestion des services de santé. Centre Africain d'études supérieures en gestion, Dakar, November 2013(23).

Finally, various graduates from different nursing schools in Burundi performed internships at GFC and wrote their theses using GFC data.

#### 2.5 ADVOCACY AND TÉMOIGNAGE

#### 2.5.1 COMMUNITY LEVEL

Health promotion (HP) activities raised awareness among religious, political and social leaders at the local level. The fistula ambassadors played an important role as first hand witnesses and advocates for recognition of the disease and for destigmatization.

#### 2.5.2 NATIONAL LEVEL

In Bujumbura, the capital, active lobbying and the development of strong partnerships facilitated:

- 1. the formal decision to make OF care free of charge as part of free sexual and reproductive health care
- 2. the development of a national strategy to prevent and cure OF
- 3. the establishment of a national technical platform on OF care
- 4. the process of recognizing GFC as a National Referral Center for Fistula Care

#### 2.5.3 INTERNATIONAL LEVEL

MSF has demonstrated its capacity in delivering high quality OF care for large numbers of patients at GFC through the following:

- 1. Launching a global multimedia series on maternal health, with OF featuring as a major topic(24)
- 2. Participating in the Global Fistula Map project which showed that in 2013 GFC was the fifth largest fistula care provider worldwide in terms of number of interventions(25)



the vagina and the bladder or rectum due to the babies head pushing too long on the birth can



- Delivering several presentations at the International Society of Fistula Surgeons Conference (2012 Dhaka, Bangladesh and 2014 Kampala, Uganda) covering different aspects of GFC's activities
- 4. Publishing various OF-related research from GFC (mentioned above)
- Being listed by UNFPA as a principal partner in the worldwide "End-fistula" project
- Being recognized as one of the largest fistula care providers with over 1000 surgeries per year (all MSF sections together), often in (post) conflict zones

#### **2.6 SUSTAINABILITY**

The integration of GFC into GRH was planned from the outset of the project. After two years of very little interest and cooperation from the Hospital Director, the integration process advanced substantially at the end of 2014, nine months before hand-over.

Major accomplishments during that period included:

- 1. Major rehabilitation work in the surgical block and fistula village
- 2. Recruitment of new staff
- Intensive training and coaching of medical, paramedical and supporting staff in their new roles
- Establishment of new partnerships (provision of food by the World Food Program; provision of consumables, instruments, and continuous surgical training by UNFPA)

- 5. Engagement of the hospital directorate and administration in the daily management of the fistula ward
- 6. National recognition of GRH as the national referral center for OF care
- A hand-over ceremony in the presence of national, provincial and local authorities.

Major shortcomings were:

- Lack of proper planning and preparation before the end of 2014 (the process should ideally have started much earlier).
- Incomplete surgical training of the new director come surgeon. This has resulted in a reduced number of surgical repairs being performed during the months following the hand-over.

#### 2.7. COST PER PATIENT

The cost for those patients who only needed catheter treatment was far less than for those who needed repeated surgery or had severe complications. However, a detailed analysis of the cost per patient per treatment modality and outcome is beyond the scope of this report. The average cost per patient (total annual budget/total number of patients treated) allows a crude comparison with other similar projects.

The total budget for the five year project was  $\in$  3,616,026. As the total number of new cases admitted to GFC was 1645 (including 86 non-OF cases), the crude cost per treated patient was around  $\notin$  2,200. This includes the cost of re-intervention for patients needing repeat surgery or returning with complications.



### **3. RESULTS**

The purpose of this section is to provide a global overview of the GFC project and thus only the main results of the project are presented. A more detailed analysis is available in the final project report  $2010 - 2015^{(2)}$ 

#### 3.1 RECRUITMENT OF OBSTETRIC FISTULA PATIENTS

During the years 2011 and 2012 most patients were recruited through active case finding (Figure 1). However, as from 2013 this number declined steadily. The number of patients being referred from health structures was as from 2012 onwards stable, while the number of self-referrals fluctuated each year. This resulted in having proportionally the most patients being recruited by the health structures in 2015 (Table 1). Figure 1: Mode of recruitment of obstetric fistula patients at Gitega Fistula Centre, Gitega, Burundi (January 2011\*- June 2015)



\* 2010 data not available

Table 1: Proportional mode of recruitment of obstetric fistula patients at Gitega Fistula Centre, Gitega, Burundi (January 2011\*- June 2015)

	2011	2012	2013	2014	2015
self-referral	15%	17%	15%	27%	22%
referred by health structure	14%	21%	30%	33%	40%
active case finding	48%	60%	54%	39%	36%
Others	23%	2%	1%	2%	3%

\* 2010 data not available



Figure 2: Effectiveness of the active case finding approach for recruiting OF patients, Burundi, (May 2010 - June 2015)

While the number of active case finding sessions steadily increased from one year to the next, the overall number of women attending these sessions began to fall in the latter half of the project (Table 2) as did the number and proportion with an OF (28% in 2010 to 9% in 2015, figure 2).

Table 2: Total sessions per year and average number of women presenting per session, Burundi (May 2010 - June 2015)

	2010	2011	2012	2013	2014	2015
Number of sessions	3	18	28	54	93	53
Number of women presenting per session	45	58	25	21	9	9

Figure 3: Number and type of obstetric fistula cases admitted to Gitega Fistula Centre, Burundi, (April 2010 - July 2015)



#### 3.2 CLINICAL PROFILE OF WOMEN Admitted to GFC

During the course of the project, there were a total of 2038 admissions: 1559 first admissions and 479 re-admissions for women whose fistula(e) could not be closed in a single attempt. Total admissions steadily increased during the first half of the project and then began to decline in the latter half of the project, likely mirroring a marked lowering of the OF prevalence. Overall, out of the 1559 first admissions, 1443 patients had one OF, 113 had two OF and 3 had three OF, representing a total of 1678 OF.

From 2011, the proportion of patients who sought care more than one year after developing their VVF declined year after year, while the proportion of patients presenting within one year of developing their fistula increased steadily over time, to 84% in 2015.

Among women with a VVF, the fistula was caused by prolonged labor in 80% of cases.







### Figure 5: Number and type of "Obstetric Fistula" intervention per month in Gitega Fistula Center, Burundi (April 2010 - July 2015)

TPR= total perineal repair or RVF IIb; RVF= all RVF types excluding RVFIIb







Table 2: Surgical outcomes at discharge among OF patients (excluding patients with a RVFIIb and patients with two or more fistulae) treated at Gitega Fistula Center, Burundi (April 2010 - July 2015)

	First surgery n (%)	Repeated surgery n (%)
TOTAL	1020	468
Fistula closed: Continent Incontinent	929 (77) 619 (87) 96 (13)	271 (58) 190 (70) 81 (30)
TOTAL Fistula closed + Continent	619 (61)	190 (41)

The majority of patients operated on received a VVF repair, although the annual number of VVF repairs declined steeply from 2013 onwards. The number of RVF repairs remained stable throughout the project while the number of TPRs increased significantly in 2012, stabilizing thereafter (Figure 5).

A RVF type IIb is not in the strict sense an OF; it is not a fistula at all, but a perineal tear. And it is not caused by obstructed labor, but lack of perineal care during unobstructed labor. Its surgical repair is relatively simple with a high success and low complication rate. At GFC, RVF IIb have been wrongly classified as an OF.

#### 3.3 SURGICAL AND CONSERVATIVE (CATHETER) TREATMENT AND OUTCOMES

Out of a total of 1559 women coming to GFC, 155 (10%) received conservative treatment and 1402 (90%) received surgical repair only. 118 (76%) women receiving conservative treatment subsequently required surgical treatment due to an unsuccessful outcome with urinary catheterization. Two women (<1%) did not receive any treatment due to the presence of other co-morbidities and/or complications.

### 3.3.1 SURGICAL TREATMENT AND OUTCOMES

Over the years women receiving a first surgery remained more or less stable between 70% in 2010 to 64% in 2015. However for three or more attempts we saw that this proportion doubled from 10% in 2010 to 23% in 2014 (Figure 6). In 2015 this decreased to 19% which is most likely because of the medical doctor's training in OF surgery did not reach the advanced level, and three or more attempted surgeries are among complicated OF patients.

Closure rates and continence rates at discharge after OF surgery were 77% and 61% respectively at the first intervention, and 58% and 41% at repeated intervention (Table 2). Although it would be important to understand what happened to those women whose fistula was not closed and / or had residual incontinence after the intervention(s), however the complexity of the analysis and interpretation of these phenomena were beyond the scope of this report.

#### 3.3.2 CONSERVATIVE (CATHETER) TREATMENT AND OUTCOMES

A total of 198 patients with OF arrived at GFC within six weeks of the causal delivery. Of these patients, 150 (76%) patients were health center referrals and, the remaining patients. 48 (24%) were self-referrals. 155 patients (78%) received a bladder catheter as early VVF treatment. 37 (24%) were cured without further intervention, 76 (49%) were operated on immediately after the failed catheter treatment, of which 56 (74 %) left the hospital continent. Forty-two (27%) were still awaiting surgery.

#### 3.3.3 MORBIDITY AND MORTALITY

The main morbidities or complications observed among all admissions were:

83 (4%) lower urinary tract infections, 52 (3%) high urinary tract infections, 24 (1%) early breakdown of fistula repair, 9 (<1%) post-operative bleeding, 4 (<1%) infection of episiotomy and 205 (10%) non-specified complications that were successfully treated at GFC.

Overall wound infection rate was 3.5%

Five patients (0.3%) were referred to either GRH or a tertiary level hospital in the capital Bujumbura: 3 before surgical intervention and 2 after first surgery. Table 3: Status of fistula closure and continence at exit, 3 and 6 months follow up among patients treated at Gitega Fistula Center, Burundi (January 2012 – December 2014\*)

	At discharge n (%)	At 3 months follow-up n (%)	At 6 months follow-up n (%)
TOTAL	798	732 (92)	608 (79**)
Fistula closed			
Continent	718 (92)	617 (84)	549 (92)
Incontinent	80 (8)	114 (16)	58 (8)
Fistula breakdown		1 (<1)	1 (<1)

\* Only the years 2012-2014 were included as the follow-up through telephone consultations only started in January 2012 and six months follow-up could only be analyzed from patients who were discharged by the 31st of December 2014.

\*\* 33 patients were not followed up at six months due to an early appointment at GFC.

Two (0.1%) patients died after surgical intervention and before being referred to Bujumbura.

Two (0.1%) patients left GFC before any intervention.

According to MSF criteria, the morbidity and mortality rates were within acceptable margins.

### 3.3.4 THREE AND SIX MONTHS FOLLOW-UP

At three months follow-up, 92% of the women could be telephone-contacted which decreased to 79% by six months follow-up (Table 3). Main reasons for not being able to connect to the women were change of telephone number, telephone number no longer existing, or receiving an unknown person.

Residual incontinence at three months follow-up saw a huge increase. This can be partially explained by the fact that women would not want to disclose their continence status at discharge as they desired to go home. However we do not have any objective means to measure this. There is also no explanation for the decrease of incontinence at six months follow-up.



# 4. DISCUSSION

This multidisciplinary OF project was innovative in many aspects as demonstrated by: the early establishment of strong partnerships, the set-up of several large data bases, the use of a telephone hotline, the introduction of specific clinical protocols, the extensive follow-up program, the extensive outreach activities, the establishment of a pool of expert surgeons, the introduction of new physiotherapy techniques, the extensive operational research, the surgical training being based on the FIGO manual, the integrated psycho-social assistance, the educational and family planning program, the strong advocacy efforts, the intensive hand-over process and the capitalization effort.

The MSF experience of implementing the OF program in Gitega provides a number of lessons learnt, highlights key areas that need addressing and provides potential solutions/approaches to consider for future OF projects.

#### **4.1 PREVENTION**

Prevention of obstructed labor by timely caesarian section will end OF worldwide. The MSF OF strategy addresses prevention by strengthening emergency obstetrical care (EmOC), albeit not always at the same location as the fistula centre. When OF care is integrated within a hospital with a maternity unit, quality EmOC should be available. If it is not, MSF should provide support for this. This was the case in two other MSF fistula centers, so much so that the EmOC support superseded OF care as the main part of the project. This was not the case in Burundi, where the EmOC part of the program was actually provided at an MSF-run EmOC unit in a separate province, several hours drive away.

#### 4.2 CLOSURE, CURE AND CLINICAL SUCCESS

International consensus about basic definitions of clinical success in OF care, and more specifically in OF surgery, does not yet exist<sup>26</sup>. Comparing OF treatment outcomes between programs is therefore a challenge.

Closure rates: Closure rates seem to be associated with the amount of scarring, the type of fistula, the experience of the surgeon and most importantly, the number of previous surgeries<sup>(27)</sup>. To compare closure rates from one program to another thus requires that these confounding variables be controlled for and this was far beyond the scope of this report. The closure rate at discharge of first-time OF surgery is possibly the only indicator that allows for reasonable comparison. At GFC the closure rate of 77% was lower than the reported 94% among East-African OF patients<sup>(28)</sup> and the generally accepted 85% WHO standard<sup>(29)</sup>. Although below the thresholds for which we do not have an explanation, we consider this to be a satisfactory and realistic outcome.

Continence rates: In the absence of a clear definition of post-repair continence, continence rates could not be compared.

Clinical success: Closure of the fistula might be viewed as a success by the clinician, and a fully continent patient might be regarded as a cured patient. However, a patient might define "being cured" very differently, i.e. as being continent AND being able to deliver a healthy baby.

The international fistula community needs to urgently develop definitions of success, both from a clinician's as well as a patient's point of view. MSF can and should contribute to this process through quantitative and qualitative research.

### 4.3 PREVALENCE, INCIDENCE AND JUSTIFICATION FOR INTERVENTION

Results from the UNFPA prevalence study conducted in 2013 did not match the story told by the GFC data. UNFPA estimated a national OF prevalence of 3550 cases, and an incidence of 750 new cases per year. Recruitment data from GFC indicated that in 2013 the large majority of the backlog



of OF patients had already been treated. Furthermore, the low patient recruitment rate for the fresh fistula study suggested a much lower incidence than UNFPA reported. A reliable OF prevalence study is notoriously difficult to conduct because of the relative scarcity of OF and the complexities surrounding the OF case definition. The Demographic Health Surveys (DHS) Program of the United States Agency for International development (USAID) has published recommendations on how to conduct a robust OF prevalence study<sup>(30)</sup>. MSF should insist on the implementation of this methodology in each country where it wants to develop fistula activities and where a prevalence study is foreseen or needed. In the absence of DHS based data, MSF should gather all available fistula data in the country or region of interest, and analyze these data critically in order to estimate a proxy prevalence/incidence. Organizing a pilot fistula campaign in a well-chosen location, in collaboration with reliable partners, might provide the next step. In this way, relevant field information can be gathered on the feasibility and relevance of setting up a fistula center in a particular region. Once the fistula center has been set up, close monitoring is essential in order to respond appropriately to over- or underestimated needs.

#### 4.4 CASE DEFINITION AND ITS CONSEQUENCES

Incorrectly including RVFIIb in the case definition of an OF (see above) had some serious consequences:

- 1. In 2014, only 13 OF repairs were performed per month instead of the 21 reported when the RVFIIb repairs were included in the numbers. In 2015, this number dropped further to 9 per month (translating to approximately two OF repairs per week). This low number hardly justifies the presence of a permanent fistula center and essentially jeopardizes the quality of care provided. By monitoring the correct number of OF repairs, the handover strategy may have been different; the systematic referral of cases to REMA Hospital and/or CHUK would likely have been implemented sooner and unnecessary resources would likely have been saved. Unfortunately, data on the level of activity at GFC six months after the hand-over were not available.
- Including RVFIIb repairs in the outcome data for OF repairs artificially improved the closure and continence rates as these interventions have a higher success rate than a true OF repair. Separate analysis should have been routinely performed. This was particularly relevant for 2014 and 2015 when 40% of all interventions were RVFIIb repairs.

Extensive tissue damage may make fistula closure technically impossible. At GFC, it was not possible to analyze how many OF patients were considered "inoperable" and for what reasons. In the absence of a common case definition, defining an OF as "inoperable" depends largely on the level of expertise of the fistula surgeon. Patients may receive too many surgical attempts with very little chance of success, or may be denied the chance of being "cured" if the surgeon incorrectly declares a patient to be "inoperable". The most experienced OF surgeon, being the referent surgeon at head quarter's level, should make the final call whether to continue or stop surgery in a patient with a complicated OF. Once a patient is considered to be inoperable, all

measures should be taken to assist the patient medically and psycho-socially in the best way possible, in principle for the rest of her life.

Residual incontinence after fistula closure is ill defined. Its quantification, classification and treatment are yet to be standardized. At GFC, outcomes of conservative or surgical treatment of residual incontinence could not be analyzed. Guidelines, preferably as part of operational research, need to be put in place to allow for a proper evaluation of the different treatments available.

The aforementioned points highlight the complexity of a fistula project and make the important case for ensuring continuous close supervision and evaluation from a fistula referent/expert at the Headquarters level. This was only the case during the first two years at GFC, when the head quarter fistula referent was also the surgeon at GFC. At project level, the continual presence of a doctor acting as the local expert is indispensable, to oversee daily medical care as well as timely analysis and correction of data, in close cooperation with the medical coordinator.

#### **4.5 RECRUITMENT**

The active case finding approach used to recruit OF patients required intensive resources and its success seemed to depend principally on a relatively high prevalence of OF. As time went by and the prevalence of OF decreased, intensifying these case finding efforts was met with decreasing marginal gains (so called 'diminishing returns').

The number of medical staff at public health structures trained by the outreach teams was impressive and probably unique. It demanded intensive resources and favorable conditions such as a relatively small and accessible country and well established relations with the local authorities. The increase in health structure referrals to GFC over time strongly implies that the training was effective. However, the cost-effectiveness, reproducibility and impact of this approach in other contexts is unclear and this merits future research.

Training medical staff seemed to be the most sustainable way of recruiting patients, and informing the population through different media channels the most cost-effective. This was true for patients with long standing OF as well as fresh fistulae.

#### **4.6 MONITORING AND RESEARCH**

The opportunity to establish an extensive medico-socio-anthropological profile of the patients was missed. In other words, at the end of the project, we knew very little about the patients we had treated. This hindered our ability to advocate on their behalf within the political and medical arena. The early involvement of anthropologists and /or psychologists would be very useful in the future.



The amount of data gathered in this project was enormous and therefore difficult to manage. Only a part of the data was used or could be used. Better data management could have contributed to better strategical decisions and in-depth analysis of the surgical results and outcomes of the project together with the effect of introducing various treatment adjuncts such as the new physiotherapy methods. Projects of this complexity need continuous guidance and follow-up by a data manager or operational researcher.

#### **4.7 TRAINING**

Providing high quality training in fistula surgery is a major challenge in any given setting. It demands considerable long-term efforts and committed engagement of the trainer and the trainee. Both the trainer and the trainee need to have specific qualities, the set-up of the fistula center needs to be adapted to provide the right environment for training and there needs to be an adequate pool of appropriate patients to facilitate sufficient hand-on training. A wellestablished trainer should be involved at an early stage to assess the relevance and feasibility of setting up a surgical training program. The long-term engagement of a well- trained national surgeon is absolutely vital for a successful hand-over, although provision of training should not necessarily fall under the remit of MSF.

#### 4.8 COLLABORATIVE PARTNER-SHIPS AND MINISTRY OF HEALTH INVOLVEMENT

The establishment of partnerships was at times laborious and frustrating. However, it was an important part of this project for the following reasons:

- MSF could benefit from the knowledge and networks already present in the country (HI).
- Partners were able to cover certain aspects of the project where MSF had less know-how (such as physiotherapy and social reintegration (HI)) and were also able to take over certain responsibilities after GFC was handedover (UNFPA).
- 3. Integration of GFC within the hospital and the hand-over would have been



impossible without a strong partnership between MSF and the Hospital Director during the second half of the project.

- Outreach activities demanded strong partnerships with local authorities and NGOs.
- 5. A partnership with the MoH was essential, particularly in regard to the execution of an effective national program to prevent and cure OF.

#### 4.9 COSTS

Offering OF treatment free of charge is essential for this group of vulnerable patients and should be part of a national MoH strategy. Once a fistula center has been established, the cost per patient depends largely on the number of patients being treated. Below a critical threshold the cost per patient becomes unacceptably high, as the MSF fistula project in Chad has shown<sup>(1)</sup>. On the contrary; the cost per patient is considerably lower when numbers are high and when most patients selfrefer, as demonstrated in the MSF fistula center in Jahun, Nigeria which has been running for seven years now. At GFC, fully deployed outreach activities utilized one third of the annual budget (although of note, some of these costs went towards recruiting fresh fistula patients for the research study). To better understand the cost of implementing an OF project like GFC, a cost-effectiveness study would be justified.



### **5. CONCLUSION**

The MSF multidisciplinary OF care project in Gitega, Burundi, combined high quality care and innovation and treated over 1500 women helping them to restore their dignity. Major lessons were learnt during the five year project period regarding nationwide recruitment of OF patients, the proper classification of OF, the use of relevant outcome indicators, the management and analysis of a large amount of clinical data, the conduct of operational research, the simultaneous offer of different treatment modalities, the organization of a follow-up program, the establishment of partnerships, the set-up of an extensive and diverse training program, and the planning and execution of the hand-over. Providing multidisciplinary OF care is very complex and demands specific expertise and continuous monitoring. A timely assessment of the changing local needs in OF care and the built up of national capacity accordingly will always remain one of the most important challenges. MSF has shown that its approach to deliver OF care was efficient, affordable and to a certain degree sustainable. This rapport hopefully will be helpful to other OF programs in its start-up, its continuation and/or considered improvements of care for those OF patients still awaiting treatment.





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